Supporting the recovery of black individuals who use community mental health services

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Abstract

Despite a recovery orientation being mental health policy within England, the perceptions of recovery and the effectiveness of recovery-focused interventions for black individuals are under-researched. This thesis describes the development and evaluation of an intervention to support the recovery of black individuals who use community mental health services.

The Medical Research Council (MRC) framework for designing and evaluating complex interventions was the guiding scientific framework, with an embedded experimental mixed method design adopted. A systematic review and narrative synthesis identified the evidence base regarding the meaning of recovery for mental health service users. The Conceptual Framework of Recovery was developed from the review. Only one study included in the review focused on the perceptions of recovery for black individuals.

Four focus groups with 26 participants and 14 semi-structured interviews were conducted with service users who self-ascribed their ethnicity as black. The results were used to develop the Framework of Recovery Support, in which identity - (re)gaining a positive sense of self, was central to recovery. The Conceptual Framework of Recovery and Framework of Recovery Support were used to develop a component of the REFOCUS pro-recovery intervention called Working Practice 1: Understanding Values and Treatment Preferences.

The effectiveness of the REFOCUS intervention for black individuals was assessed in a pre-planned subgroup analysis of a cluster randomised controlled trial (RCT). One hundred and ten service users participated in the RCT, with 81 (74%) followed up after 12 months. The two primary outcomes were personal recovery (Questionnaire about the Process of Recovery) and service satisfaction (Client-Satisfaction Questionnaire - 8 item version). Secondary outcomes included hope, empowerment, wellbeing, quality of life, symptom levels and clinical need. Multilevel mixed-effects regression modelling, which controlled for clustering at the team level, was conducted for the analysis of treatment effect. A process evaluation embedded within the trial included interviews with eight individuals who had received the intervention.

Results indicated that the intervention had no effect on either recovery ($p=0.693$) or service satisfaction ($p=0.77$). However, the intervention significantly improved service user-rated level of met need. Overall the intervention was well-received and associated with positive experiences, however the process evaluation highlighted issues with routine implementation.

Structural Equation Modelling (SEM) was used to integrate the qualitative and quantitative findings of the trial. The SEM analysis indicated that exploring identity was associated with improved service satisfaction and personal recovery.

This thesis provides an initial evidence base for understanding and supporting the recovery of black individuals who use adult community mental health services. The findings of this thesis have important theoretical, methodological, and clinical implications which are discussed with reference to the wider literature concerning the mental health needs and experiences of black individuals.

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Abbreviations

AIC	Akaike's Information Criteria
BAME	Black Asian and minority ethnic
BEMI	Barts Explanatory Model Inventory
BME	Black and minority ethnic
BPRS	Brief Psychiatric Rating Scale
CACE	Complier-Average Causal Effect
CAG	Clinical academic group
CANSAS-P	Camberwell Assessment of Needs Short Appraisal Schedule – Patient
CANSAS-S	Camberwell Assessment of Needs Short Appraisal Schedule – Staff
CBT	Cognitive Behavioural Therapy
CCBTp	Culturally adapted Cognitive Behavioural Therapy for psychosis
CFI	Cultural Formulation Interview
CHIME	Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment
CI	Confidence interval
CJS	Criminal justice system
CMHT	Community mental health team
CPA	Care Programme Approach
CSO	Clinical studies officer
CSQ-8	Client Satisfaction Questionnaire - 8 item version
CSRI	Client Service Receipt Inventory
CTO	Community treatment order
CTU	Clinical trials unit
DRE	Delivering race equality
DSM	Diagnostic and statistical manual
EMIC	Explanatory Model Interview Catalogue
EPJ	Electronic patient journey
GAF	Global Assessment of Functioning scale
GCP	Good clinical practice
HHI	Herth Hope Index
HoNOS	Health of the Nation Outcome Scale
IAB	International Advisory Board
ICC	Interclass correlation coefficient

IMR	Illness Management and Recovery
IOPPN	Institute of Psychiatry, Psychology and Neuroscience
ITT	Intention to treat
LEAP	Lived Experience Advisory Panel
MAR	Missing at random
MANSA	Manchester Short Assessment of Quality of Life
MCAR	Missing completely at random
MeSH	Medical subject headings
MHA	Mental Health Act
MHCS	Mental Health Confidence Scale
MINI	McGill Illness Narrative Interview
MNAR	Missing not at random
MRC	Medical Research Council
NART	National Adult Reading Test
NSUN	National Survivor User Network
OPCS	Office of Population Censuses and Survey Classification
QPR	The Questionnaire about the Process of Recovery
RCT	Randomised controlled trial
RFS-SU	Recovery Fidelity Scale – Service User
RMR	Root mean square residual
RR	Relative risk
SBCM	Strengths-based case management
SEM	Structural equation modelling
SEMI	Short Explanatory Model Interview
SF-SU	Sociodemographics Form – Service User
SLaM	South London and Maudsley NHS Foundation Trust
SMD	Standardised mean difference
SRN	Scottish Recovery Network
TEWV	Tees, Esk and Wear Valley NHS Foundation Trust
VIF	Variance inflating factor
VTP	Values and Treatment Preferences
WEMWBS	Warwick Edinburgh Mental Wellbeing Scale
WRAP	Wellness Recovery Action Plans

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For James

"God only knows what I'd be without you"

Chapter 1 Introduction

1.1 Thesis overview

Research has shown that people from black backgrounds experience mental health inequalities in terms of both need and the care received. Studies have demonstrated increased rates of mental illness [1,2], more complex pathways to care including criminal justice system involvement (CJS) [3], increased use of the Mental Health Act (MHA) [4], and poorer satisfaction with services [5,6,7].

Within mental health services in the NHS there is currently a drive towards promoting recovery. The most widely used definition, proposed by William Anthony, defines recovery as: *"A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness"* [[8] p527]. Despite a large amount of service user-led research into recovery, very little has been conducted into the perspectives of recovery for people from black communities, with even less attention focused on how to support the recovery of black individuals. This thesis involved the development of a framework for how adult community mental health services can support the recovery of black individuals. This framework was used to inform a section of a manualised recovery intervention which was evaluated in a cluster randomised controlled trial (RCT).

1.2 Terms used throughout the thesis

1.2.1 Race, culture and ethnicity

The notions of race, culture and ethnicity used within the literature are often unclear, with many researchers using ethnicity as a proxy measure covering the other two concepts. The lack of clarity surrounding the terms within research and practice can lead to misunderstandings and a poor response to need [9]. Race is perhaps the most contentious and fundamental of these concepts particularly given the present and historical impact of racism and racial oppression. Although arguably having some biological origins, race is a social category in which people are classified into groups on the basis of characteristics classed as socially significant [10]. These features typically include skin colour, hair colour and eye shape, often under the misguided belief that race is a purely biological construct. Throughout history, race has been viewed as fixed, with a biological notion of race serving as the justification for the idea that one race is superior to another [9]. However, it is now widely accepted that the biological basis of race is *"flawed"* [11]. Not only is the genetic variation within people of the

same race often greater than between individuals of different races, no complete set of genetic markers defines any one racial group. Instead, the classification of race based on assumed biological difference serves social purposes, notably the stratification of global and national populations [11]. This is not to say that race as a category does not exist, instead it stresses race as a social category, and one that has an impact on how people are perceived, particularly through the application of racial stereotypes and assumptions. Race has been summarised as a "*concept which signifies and symbolizes social conflict and interests by referring to different types of human bodies*" [[11] p54-5]. This definition of race as a socially constructed category based on socially significant (physical) characteristics was used within the thesis.

Culture on the other hand was broadly defined within the thesis as *"a common heritage or set of beliefs, norms and values, which are shared among a large group of people"* [[10] p17]. It can be seen as a linkage between people, including their shared ideas, habits, non-material properties and rules, with Sewell describing it as *"the substance of cohesion between people"* [[9] p19]. Furthermore, culture helps us to make sense of the world [3]. Within this definition, culture can relate to worldviews, traditions and customs as well as behaviours and attitudes; it extends beyond the individual to include families and communities. In shorthand, culture is often referred to as the way we live [11].

In contrast to race which is commonly seen as fixed in nature, culture is fluid, dynamic and ever-changing. Individuals choose to identify with and belong to different cultures and sub-cultures at various points in their lives. This is especially true where individuals live side by side with a mix of cultures, such that interaction between different groups shifts and changes the culture. Culture is often confused with race, particularly within mental health services, such that there is a misguided assumption that people of different races have different cultures, and that people in the same racial group share culture. However, any attempt to define the culture of a group will inevitably overlook individual differences [9], a finding important to later chapters of this thesis. Culture also describes institutions, organisations and different professions, including mental health services, such that culture provides the ethos underlying certain behaviours deemed acceptable. Finally, culture may also be used in an experimental or situational sense, whereby individuals are grouped based on some attribute (e.g. youth culture) or experience (e.g. drug culture), although the value of this use of the term culture has been questioned [11].

As well as overlapping with race, ethnicity is frequently confused with culture, with researchers often assuming that people of the same ethnicity share the same culture [10]. Ethnicity is neither a fixed nor easily defined concept but instead includes a range of attributes and factors such as language, religion, skin colour, heritage and country of birth for example. The physical appearance and/or social behaviour of people from within the same ethnic group may differ [11]. Ethnicity is primarily based on self-definition and can indicate what is important to the person, including what and whom they identify with. Ethnicity may also partly be determined by how other people see the person. For instance, in a society where race and racism are prevalent concepts, ethnicity may be defined by race.

Ethnic origin which relates to physical appearance, language and religion, has been differentiated from ethnic group which is more self-definitional in nature [9]. In essence, ethnicity involves a sense of belonging. However, although ethnicity involves self-definition, it should not be confused with identity which relates to how the person views themselves as a unique individual, often within a particular racial, ethnic or cultural group. Identity as a concept will be discussed throughout the thesis, most notably within Chapter 5.

Given the complexity of ethnicity, the term remains confused within both research and clinical practice. A report into the data collection and classification of ethnicity surmised that the following areas were all important: "*country of birth, nationality, language spoken at home, parents' country of birth in conjunction with country of birth, skin colour, national/geographical origin, racial group and religion.*" [[12] p12]. This definition of ethnicity has been extended to propose a two-dimensional definition which emphases the complex social nature of ethnicity, including the impact on a person's identity and social relations. Unlike other definitions of ethnicity which tend to focus on attributional characteristics, Ford and Harawa propose that ethnicity should be defined as a context-specific construct with an attributional dimension such as culture, skin colour etc. and as a relational construct where ethnic groups are located within a social context, including a social hierarchy [13]. It is argued that whilst the attributional dimensions are useful in describing and understanding personal identity and sociocultural characteristics, the impact of society and social location is negated. Furthermore, the authors suggest that the relational dimension to ethnicity is particularly useful in understanding ethnic health inequalities [13]. This wide ranging definition of ethnicity which encompasses both the features defined above and the social context has been used as the definition within this thesis.

The concepts of race, culture and ethnicity, and how they are currently perceived within society, are summarised below in Table 1.1, which was adapted from [11].

Table 1.1: Race, culture and ethnicity

Concept	Characterised by	Perceived as	Societal perception	Expert consensus
Race	Physical appearance	Physical, permanent	Genetically determined	Socially constructed
Culture	Behaviour, attitudes etc.	Social, changeable	Passed down by parents/parent substitutes	Variable and changeable blue-print for living
Ethnicity	Sense of belonging	Psychosocial, partially changeable	How people see themselves in terms of their background and parentage	Culture - race mixture

1.2.2 Racism, racial discrimination and racial prejudice

Racism relates to discrimination based on race. Bhugra and Bhui differentiate racism, which they see as beliefs relating to the ideology that one race is inherently superior to another, from racial discrimination which is rooted in the actions of others and results in disadvantaging people from certain racial groups [14]. In this sense, individuals may hold beliefs that are not consistent with racism, but may however act in a racially discriminating way. Institutional racism, defined as the collective failure of an organisation, involving attitudes and behaviours which disadvantage people from minority ethnic backgrounds, also falls within this latter category of racial discrimination [15]. Fernando further suggests that racism and racial discrimination can be separated from racial prejudice, which he defines as a "*psychological state, a feeling or attitude of the mind*" [[11] p21] including the misperceptions and rejections of others based on race.

1.2.3 Black (Asian), and minority ethnic (BME / BAME)

The term 'minority ethnic' and 'black and minority ethnic' have been used throughout the thesis, however they are not without problem. For instance, 'minority ethnic group' is synonymous with disadvantage, including within mental health services. However this term has been used in preference to the term 'ethnic minority' which implies that only individuals in a minority have an ethnicity. The term BME has more recently been extended to Black, Asian and minority ethnic (BAME). The terms BME and BAME do not relate to homogenous groups. Throughout the thesis, the term BME backgrounds is more commonly adopted as it

aims to reflect the fact that many individuals were born within the UK, but it is their heritage which links to and includes them within this category.

1.2.4 Black individuals

The focus of this thesis is on individuals from black backgrounds. The term black primarily refers to people from the African Diaspora and is used in this context to include the categories black African, black Caribbean, black British and black other. The term black may also be used by individuals who ascribe their ethnicity as 'politically black'. This is a term based on a notion of otherness, and a black-white distinction which individuals from non-white backgrounds, including people from Asian descent for example, may identify with [11]. Within the thesis, the Office of Population Censuses and Surveys (OPCS) census categories of black African, black Caribbean and black British are used in preference to the term African Caribbean. Although the term African Caribbean is often used synonymously with black Caribbean, it has been avoided here due to its frequent use within research as a simplified grouping of ethnic categories, used to refer to all people of black descent [16].

Within the qualitative sections of the thesis (Chapter 5 and Chapter 8), self-ascribed ethnicity was used to determine inclusion. Individuals who self-ascribed their ethnicity as politically black were eligible for the qualitative study. In contrast, within the RCT, inclusion status was determined by OPCS census categories as recorded on the electronic health record system - electronic patient journey (EPJ). Although the focus of this thesis is on identity, the prominence given to the term black individuals throughout reflects the notion that in mental health services, the patterns and experiences are consistent at a racial level (e.g. black) despite the wide heterogeneity of the disparate groups and individuals referred to.

1.3 Rationale, aims and hypotheses

1.3.1 Rationale for conducting the research

There is a wealth of UK-based research highlighting different ethnic inequalities in mental healthcare. Within this context, ethnic inequalities refer to the difference in need, treatment, and outcomes of mental healthcare experienced by members of different ethnic groups. Although these inequalities will be covered in detail in Chapter 2, four key areas contributed to the rationale of this thesis. These were i) increased incidence and prevalence of mental health problems; ii) complex pathways to care, iii) increased use of the MHA including involuntary admission, and iv) poorer satisfaction with services.

Firstly, there is strong evidence that rates of serious mental illness, and most notably psychosis, are elevated in people from all minority ethnic backgrounds, and particularly for black individuals [17]. A recent systematic review and meta-analysis of the incidence of psychosis highlighted that rates of all psychotic illnesses were significantly raised in minority ethnic groups compared to the white British population, but most consistently so for people from black backgrounds [18].

Secondly, in a systematic review assessing ethnic variations in pathways to specialist mental health services, five main areas of concern were raised, including more complex pathways to care [19]. Further studies including systematic reviews and meta-analyses have indicated that the complex pathways to care are apparent from the first episode of illness [3,20,21].

Thirdly, individuals from black communities are disproportionately detained under the MHA and are three times more likely to be detained than white British individuals [4,22]. Furthermore, all individuals from BME backgrounds were over-represented in terms of the number of people on community treatment orders (CTOs)[6].

Finally, BME individuals were more likely to experience poorer engagement with services and a lack of continuity of care [19]. This was coupled with poorer satisfaction with services, particularly concerning the treatment options available and the lack of talking therapies offered [6].

Recently, interest in promoting recovery within mental health services has increased [23]. Driven largely by service user movements in the US, UK, Australia and New Zealand, the notion of recovery has rapidly gained momentum within mental health practice and policy [24,25]. Unlike clinical recovery which stresses a biomedical approach to mental illness predominantly focused on symptom alleviation, personal recovery focuses on the individual's journey and their experiences [25,26].

This thesis was conducted within the context of a five-year NIHR-funded applied research programme grant - the REFOCUS programme. The overall aim of the programme was to increase the recovery-orientation of community mental health teams working within the NHS. In particular, the REFOCUS programme involved developing a robust evidence base for recovery-orientated practice. This included developing a new manualised recovery intervention, evaluated within a cluster RCT [27].

Services which focus on recovery may be one way of tackling the poorer experiences of black individuals within the mental health system. However, despite a large amount of literature defining and conceptualising recovery, it is predominantly based on majority populations. For instance, O'Hagan notes that the recovery literature is very *"monocultural"* [[28] p2], whilst, Jones and colleagues reported an absence of attention to race, culture and ethnicity in their review of the recovery literature [29]. Understanding the perspectives of recovery and the factors perceived to support recovery are paramount when designing a recovery-orientated service, particularly if services are to meet the needs of individuals from a diverse range of backgrounds [30]. In addition to this lack of evidence, few studies have been conducted into the effectiveness of recovery-orientated services and interventions for people from black backgrounds within the UK. Taken together these findings provided the rationale for further work to address both the perspectives of recovery for black individuals, and to assess the effectiveness of a pro-recovery intervention within this population.

1.3.2 Aims of the thesis

Based on the evidence gap identified above, the main research question addressed in the thesis concerned how community mental health services could support the recovery of individuals from black backgrounds.

To address this research question, the thesis had three aims:
Aim 1 – To develop a Framework of Recovery Support based on the initial theory phase of the project.

Aim 2 – To use the Framework of Recovery Support to develop a component of the REFOCUS pro-recovery intervention.

Aim 3 – To test the effectiveness of the intervention within a cluster RCT of individuals from black backgrounds who use community mental health teams (CMHTs).

Each aim was met by a number of specific objectives described within each chapter.

1.3.3 Hypotheses under investigation

The cluster RCT aimed to test the effectiveness of the REFOCUS Intervention for black individuals who use adult community mental health services. Two hypotheses were tested in the trial:

Hypothesis 1 (recovery): Black individuals assigned to the intervention arm will experience greater improvements in recovery outcomes as measured by the Questionnaire about the Process of Recovery (QPR) compared to those receiving standard care.

Hypothesis 2 (satisfaction): Black individuals assigned to the intervention arm will experience greater improvements in service satisfaction as measured by the Client Satisfaction Questionnaire – 8 item version (CSQ-8) compared to those receiving standard care.

1.3.4 Scientific framework

The scientific framework for this thesis was the Medical Research Council (MRC) framework for designing and evaluating complex interventions [31]. Within the framework, complex interventions are defined as those which include multiple components, each of which may interact. Furthermore, complexity includes the range of potential target outcomes as well as variability in the target population. The intervention developed and tested within this thesis met the definition for a complex intervention.

The MRC framework includes four phases in the development and testing of a complex intervention. These four phases correspond to i) development, ii) feasibility and piloting, iii) evaluation and iv) implementation, and are shown in Figure 1.1. Although presented as stages, this is not a linear process but is instead cyclical in nature, with interactions occurring within and between stages.

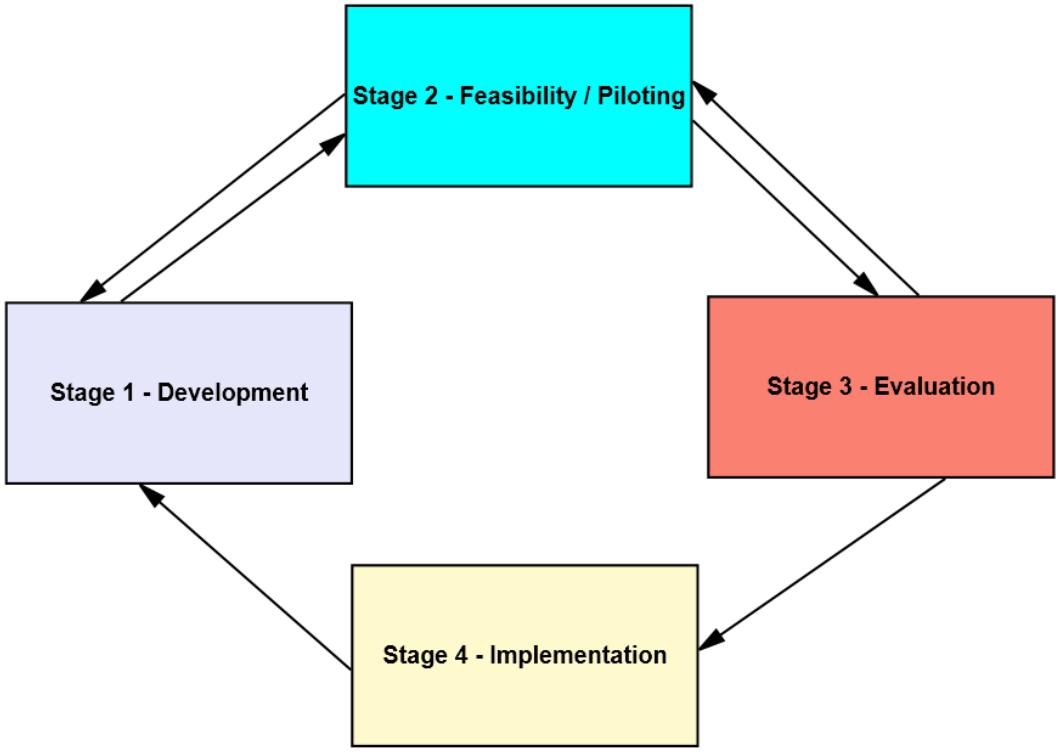


Figure 1.1: MRC framework for designing and evaluating a complex intervention

Stage 1 Development: The overall aim of the development stage is to develop and fully describe the intervention. Part of this development process involves identifying and / or developing a coherent theoretical basis for the intervention which may include the identification and appraisal of existing evidence. Where the evidence base is limited, new primary research such as qualitative investigations are recommended. Furthermore, the outcomes of the intervention should be specified and the processes of the intervention, including the anticipated impact on the target population, modelled.

Stage 2 Feasibility / piloting: Three main areas are covered in the feasibility and piloting stage. These involve testing the procedures involved in the intervention to ensure they are acceptable and feasible, estimating recruitment and retention and determining the sample size required for a definitive trial. Procedures for both the intervention and trial can be tested to ensure they are acceptable to the population of interest and to the individuals involved in delivering the intervention.

Stage 3 Evaluation: In addition to understanding and measuring the effectiveness of the intervention, the evaluation stage should also include an assessment of cost-effectiveness. The process of change should be investigated and may be guided by the modelling process

developed in Stage 1. To understand the process of change, a process evaluation is recommended and can be embedded into different trial designs.

Stage 4 implementation: The final stage included in the framework relates to the routine implementation of the intervention in practice, including dissemination activities to ensure wider knowledge of the intervention. Implementation also focuses on the longer-term outcomes and sustained impact of the intervention. Finally, during this stage researchers are encouraged to monitor implementation to gain a better understanding of effectiveness, which would not be possible in a time-limited evaluation (such as that occurring in Stage 3).

The theory phase of this thesis is presented in Chapter 2 to 5, whilst the development of the intervention, model and manual are presented in Chapter 6. These chapters correspond to Stage 1 (Development) of the MRC framework. The evaluation stage of the thesis, which included a cluster RCT is covered in Chapter 7 to 9. This corresponds to Stages 2 (Feasibility and piloting) and 3 (Evaluation) of the MRC framework. The specific content of each chapter is now described.

1.3.5 Structure of the thesis

Following from this overview, Chapter 2 provides a comprehensive literature review into the mental health needs and ethnic inequalities experienced by black individuals. Chapter 3 and 4 provide an overview of the recovery movement within mental health practice and policy, including a systematic review and narrative synthesis of the literature defining recovery (Chapter 3). The literature reviews underpin the research questions and hypotheses, and provided the detailed rationale for the study, including the study design and theoretical perspective adopted.

Chapter 5 describes a qualitative study of the experience of black mental health services users resulting in the Framework of Recovery Support. The intervention, model and manual are developed in Chapter 6. Chapter 6 discusses how the Framework of Recovery Support was used in the development of the REFOCUS Intervention, and specifically within the development of Working Practice 1: Understanding Values and Treatment Preferences.

Chapter 7 presents the methods for the cluster RCT evaluating the intervention compared to treatment as usual within the context of CMHTs. In Chapter 8, the quantitative findings of the trial which focuses on the effectiveness of the REFOCUS Intervention and the qualitative

process evaluation capturing the experience of individuals who received the intervention, are presented and synthesised.

The discussion of the results of the trial, including the implications for the REFOCUS Model and Intervention are described in Chapter 9. An overview of the strengths and limitations of the thesis are discussed. Modifications to the REFOCUS Model are presented, alongside the implications of the thesis with reference to the wider literature. Finally, suggestions for future research are given alongside the conclusions of this thesis.

1.4 Study design

1.4.1 Philosophical assumptions and epistemology

Before discussing the study design adopted, the philosophical assumptions or worldview adopted within the thesis are discussed and the terms, ontology, epistemology and methodology briefly outlined. One of the main differences between ontology and epistemology is that the former refers to our assumptions about the nature of reality, whereas epistemology concerns beliefs about how we acquire that knowledge. Methodology is simply the tools and techniques of the research. The choice of methodology and the application of that methodology will be influenced by the underlying epistemology and ontology. Many research paradigms differ in terms of their epistemology, ontology and methodology [32]. All three areas are important considerations when designing and conducting any research study [33].

The importance of epistemology, ontology and methodology and the need to be explicit about them within the research has been highlighted by Madill and colleagues. They state that "*researchers have a responsibility to make their epistemological position clear, conduct their research in a manner consistent with that position, and present their findings in a way that allows them to be evaluated properly*" [[34] p17].

1.4.2 Epistemological continuum

The approach taken within this thesis was primarily concerned with epistemology, i.e. how we come to know reality. Two epistemological perspectives are often cited within the literature as opposite ends of the epistemological continuum, namely realism and idealism [35]. Realism is linked to a positivist worldview and idealism to relativism. Although the terms realism and idealism have been used within this thesis, there remains some degree of uncertainty regarding their use within the literature [36]. Although philosophically the concepts are

distinct, it is not uncommon for terms such as logical or experimental positivism to be used interchangeably with realism, and for naive relativism and radical constructivism to be used interchangeably with subjective idealism. It is beyond the scope of this thesis to present a full discussion of the differences in terminology and underlying philosophical assumptions, however the terms realism and idealism are briefly outlined below.

According to Hammersley the central doctrine in realism is the *"idea that there is a reality independent of the researcher whose nature can be known, and that the aim of research is to produce accounts that correspond to that reality"* [[37] p43]. At one end of the spectrum, naïve realism postulates that there is a knowable truth that exists independently of the researcher and the research process. Within this position, we are able to know and measure reality. In essence, we have an *"unproblematized direct window onto the world"* [[35] p12]. In contrast, subjective idealism adopts an anti-realist position. This perspective holds that all reality is a construction on which there is no consensus. Furthermore, there can be several constructions of the same reality. Idealists argue that social reality does not exist independently of human construction and that *"people construct the social world, both through their interpretations of it and through the actions based on those interpretations"* [[37] p44]. Within this perspective, individuals in close geographical locations can live in and experience very different social worlds.

There is a wide range of epistemological positions that are not restricted to the very extremes of either realism or idealism. Figure 1.2 outlines the continuum from naïve realism to subjective idealism and is adapted from [35].

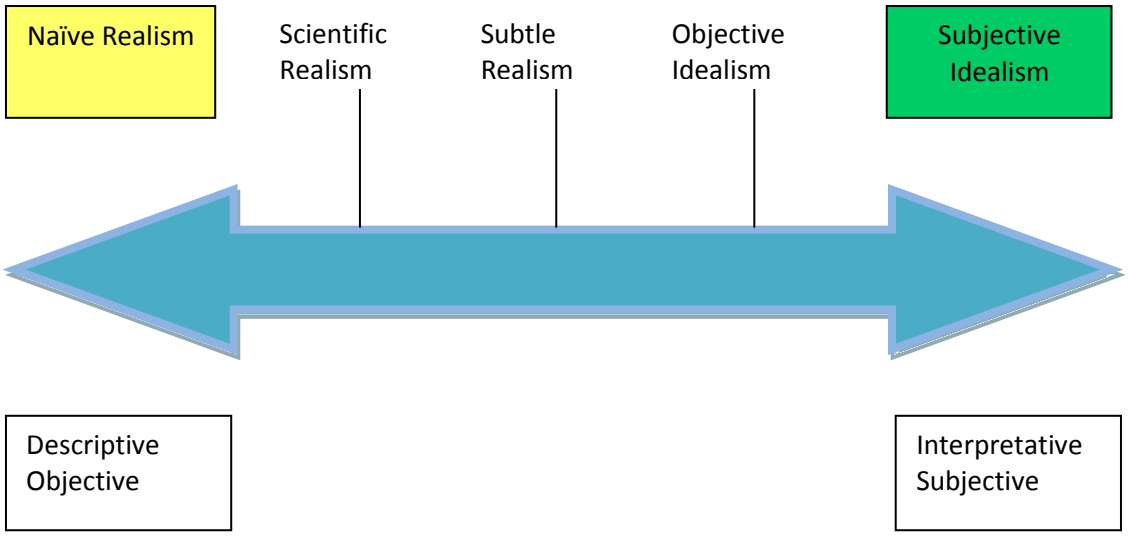


Figure 1.2: Epistemological continuum

As shown in the diagram, points along the continuum include naïve realism, scientific realism, subtle realism, objective idealism and subjective idealism. Brief definitions of each of these epistemological positions is provided in **Box 1-1**, which is adapted from [32].

Naïve realism: there is a reality that exists independently of human constructions and can be known directly.

Scientific realism: knowledge can closely approximate an external reality.

Subtle realism: there is ultimately a reality, but knowledge of reality is mediated by our perceptions and beliefs.

Objective idealism: there is a world of collectively shared understandings.

Subjective idealism: there is no shared independent reality, instead reality is made up of multiple alternative human constructions.

Box 1-1: Epistemological continuum

1.4.3 Subtle realism

The approach taken in this thesis was subtle realism. Subtle realism, as described by Hammersley, forms a link between a realist ontology and idealist epistemology [37]. Subtle realism stresses that there is ultimately a testable reality (realist ontology) but how we experience, describe and report that reality is influenced by our own culture, ethnicity, and upbringing (idealism epistemology). Furthermore, all research involves subjective perceptions and observations, therefore different methods and researchers will produce varying accounts of the same social phenomena under investigation. In essence, the researcher creates a social world rather than just presenting a social reality verbatim [33,37,38]. However, this does not preclude the existence of true and independent phenomena, which exists outside our perceptions and interpretations. It is the role of the researcher to represent this reality and to be mindful that it is only a representation [33]. For instance, when reporting the results of a study, the author is not merely reporting the experiences verbatim, but is instead reporting their construction of the participant's experience.

Hammersley states that we can *"maintain belief in the existence of phenomena independent of our claims about them, and in their knowability, without assuming we can have unmediated contact with them"* [[37] p50]. Put simply this means we can believe that there is ultimately a true reality that is independent of what we believe and know about it.

There are four key elements of subtle realism:

1. We cannot define knowledge as "*beliefs with known validity*" [[37] p50] since we can never be sure of the validity of any claims. Instead, knowledge should be defined as beliefs whose validity we are reasonably confident of.
2. Phenomena exist independent of our claims about knowledge and the validity of that knowledge. Our claims about reality do not change relevant aspects of reality.
3. Social research aims to represent reality, not reproduce it verbatim. What is deemed relevant and irrelevant is determined by the researcher (consciously or subconsciously). Therefore multiple representations of the same reality can be valid and should not be seen as contradictory.
4. Research investigates independent and knowable phenomena but we do not have direct access to this reality. All knowledge is based on assumptions.

This approach to epistemology stresses the need to monitor our own assumptions and the inferences we make. This is also true for the participants. We cannot assume that participants 'know' reality; instead they are also presenting their perception of reality, based on cultural assumptions and inferences.

Quality assessment of research is a contested area particularly for qualitative research. When using a subtle realism epistemology, research should be judged according to both validity - whether the findings are valid for the population of interest and relevance [39,40]. Within this context, relevance relates to whether the study i) addresses meaningful questions ii) adds to the existing knowledge base, and iii) is generalisable to settings beyond that in which the research was conducted [33,40].

In summary, subtle realism includes elements of both realism and idealism. Table 1.2 (Adapted from [41]), provides a comparison of subtle realism to both realism and idealism.

Table 1.2: Comparison of different epistemological positions

	Naïve realism	**Subtle realism**	**Subjective idealism**
Ontology	Only one true reality exists about which universal truths apply.	There is ultimately a testable reality, which exist independent of our constructions.	There is no reality beyond our constructions of reality.
Epistemology	We can directly observe and know reality through objective empirical observation.	Knowledge is defined as beliefs whose validity we are reasonably confident of. Our perception of	Understanding of reality is formed through an analysis of subjective accounts of knowledge.

	Naïve realism	Subtle realism	Subjective idealism
		reality is influenced by our social upbringing and background.	
Methodology	Direct empirical observation.	Empirical investigation, mixed methods research.	Analysis of knowledge structures and processes.
Research Process	Theory and hypothesis testing, deductive methods.	Abductive, theory generating and testing.	Inductive, theory generating.
Quality Assessment	Focuses on external validity, reliability and measurement of bias.	Validity and relevance to the target population.	Argues against set quality criteria as research is a social construction.

1.4.4 Criticisms of subtle realism

There are two main criticisms of subtle realism. Firstly, critics argue that by focusing on epistemology, it negates issues concerning ontology. In particular, the approach does not focus on the structure and agency of knowledge, but instead proposed a mechanism for how we know the world. Willig argues that in order to adopt a methodology for conducting research it is fundamental to also consider ontology [42]. By ignoring ontology and by suggesting that research can include aspects of both realism and idealism, Banfield argues that subtle realism represents "*a smorgasbord approach to the production of theory*" [[43] p55]. Secondly, although subtle realism was developed in response to a realist position, it has been argued that as currently defined it is adopting a post-positivist / realist approach [44]. Furthermore, the use of validity and relevance in the assessment of research quality has been criticised for holding a realist perspective [45].

Despite the above two criticisms, subtle realism can be viewed as a valuable perspective for health research were a pragmatic approach of matching research methods to research questions is adopted [36,46]. Within this thesis, subtle realism allows for a combination of methods to be used to capture the individual experience of recovery as well as group-level effectiveness data.

1.4.5 Design and methodology

Consistent with a subtle realism perspective, a mixed methods methodology was adopted to address the aims of the thesis. The overall design of this thesis was pragmatic in nature such that the research method matched the research question being addressed. For example, where the objective was to explore the experience of a particular phenomena, qualitative

methods, which traditionally are more aligned with idealism, were used. In contrast, where hypotheses related to effectiveness, experimental approaches, including an RCT (which link with a realist perspective), provided the appropriate data.

1.4.6 Mixed methods research

Qualitative and quantitative research were traditionally viewed as the two main research paradigms [47]. Qualitative research has been characterised by the types of questions it aims to address. Within qualitative research, meaning and an individual's experience are the predominant focus, with inductive methods used to allow for the identification of previously unknown processes or understandings. In contrast, quantitative research predominantly adopts deductive methods which measure known phenomena including causal relationships, proportions and patterns of association [48].

The term mixed methods research has been widely applied to any mix of research methods. For instance, studies that combine two or more qualitative study designs or two or more quantitative methods may be viewed as mixed methods [49]. However, a narrower definition of mixed methods research was adopted within the present thesis. This was based on a survey of definitions used by 15 international experts in the field of mixed methods research [47]. Based on this analysis the following definition was proposed and subsequently used in the thesis: *"Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purpose of breadth and depth of understanding and corroboration."* [[47] p123].

Researchers have argued that mixed methods research should be considered the third research paradigm alongside quantitative and qualitative research [47]. Proponents of mixed methods research state that as a paradigm, mixed methods uses the relative strengths of both quantitative and qualitative research in a pragmatic combination to answer the research question posed [48].

1.4.7 Problems with combining qualitative and quantitative research

Before discussing the main types of mixed methods research designs, including the design adopted within the thesis, three limitations with mixed methods research are briefly outlined.

One of the main concerns regarding the combination of qualitative and quantitative studies is whether or not opposing epistemological and ontological stances should be combined. The majority of qualitative research sits to the right-hand side of Figure 1.2 (Section 1.4.2) as it tends to involve interpretative methods with an underlying idealistic epistemology [34]. In contrast, most quantitative research traditionally adopts a realist stance, is considered objective and is on the left-hand side of the diagram [33]. However the expanse of different research methodologies has demonstrated that this distinction is too crude. In particular, researchers have argued that the ontological and epistemological differences between quantitative and qualitative research have been overstated, with the similarities minimised [36].

A second concern of mixed methods research is that in many mixed methods studies qualitative research is often seen as supplementary or add-on to the quantitative component. However, researchers have argued that on the contrary, qualitative work can enhance the findings of quantitative studies, and increase the internal validity of the research [50]. In particular, the use of a process evaluation employing qualitative methodologies to understand the experience of participants within an RCT is considered the gold standard within health services research [51,52,53].

The final issue with combining qualitative and quantitative research is quality appraisal. Many of the criticisms of qualitative research come from a positivist perspective, and likewise criticisms of quantitative research come from an idealist perspective. In particular, although seen as the mainstay for the critical appraisal of quantitative research, the concepts of reliability, validity and generalisability are contested within the qualitative literature [45]. Within this thesis the approach taken to quality assessment was pragmatic, with quality assessment matching the methodology for each component of the study. For example, risk of bias within the cluster RCT was discussed in Section 7.10.10, whereas there was a focus on reflexivity in the qualitative components of the study.

1.4.8 Thesis study design

There are many types of mixed methods designs proposed throughout the literature. For any mixed methods design, the following three factors need to be considered: timing, weighting and mixing of data [48].

Timing relates to the relative sequencing of the qualitative and quantitative components within the study. Although linked to data collection, timing specifically relates to when the data is analysed and interpreted. Timing within a mixed methods study can be either concurrent, whereby data collection and analysis of the qualitative and quantitative components occur at the same time, or sequential, where one type of data follows the other.

The second factor within a mixed methods study relates to the weighting of each component, or how much emphasis is placed on each data source. The weighting of the two components is determined by a number of variables including the question(s) being addressed, the target audience for the study and the relative strengths and skills of the research team. Studies vary as to whether both components are given equal or unequal weight.

Mixing relates to how the two data sources are integrated. According to Creswell, a study without integration is just a study using multiple methods and should not be considered a mixed methods design [48]. Three types of mixing are proposed within mixed methods research. These are merging, embedding and connecting. Within studies using a merging approach, the two data sources are explicitly brought together and integrated at the stage of the analysis and interpretation. Embedding on the other hand relates to mixing which occurs at the design level, whereby one source of data is embedded within a usually larger study utilising the other data source. Common approaches to embedded studies, include embedding qualitative data within a quantitative trial. Finally, connecting occurs when data analysis of one type of data (either qualitative or quantitative) leads to further data collection using the other data type.

The four most commonly used mixed methods designs have been identified as Triangulation, Embedded, Explanatory, and Exploratory designs [48]. These four approaches including the timing, weighting and mixing of the data sources are outlined in Table 1.3.

Table 1.3: Mixed methods research designs

Design Type	Definition	Timing	Weighting	Mixing
Triangulation	Triangulation aims to obtain complementary perspectives on the same problem. This combines the relative strengths of both data sources with the underlying purpose of converging the two.	Concurrent.	Usually equal weight given to both components.	The qualitative and quantitative data are merged during the interpretation and analysis.
Embedded	One data source plays a supportive role within a study where the other data source predominates. This method is used where a single set of data is insufficient to answer the research questions.	Concurrent or sequential.	Unequal weighting, with one type of data given prominence.	One data type is embedded within the other larger study design.
Explanatory	A two-phase sequential design in which qualitative data collection occurs after quantitative data collection. The qualitative data is used to explain or expand upon the initial quantitative results.	Sequential with qualitative data following quantitative.	Quantitative data is usually given greater weight.	The types of data are connected between the two phases.
Exploratory	A two-phase process in which the qualitative results are used to inform the second quantitative method. Quantitative data is used to test hypotheses and items generated by the qualitative data.	Sequential with quantitative data following the qualitative.	Qualitative data has greater weight.	The types of data are connected between the two phases.

The mixed methods design used within this thesis was an embedded experimental approach. As shown in Figure 1.3, a qualitative study (to explore the perceptions of recovery) was used alongside a systematic review to develop the intervention, model and manual. The intervention was tested in a large-scale quantitative cluster RCT. To understand the experience of receiving the intervention, the RCT included an embedded qualitative component alongside the quantitative outcome measures.

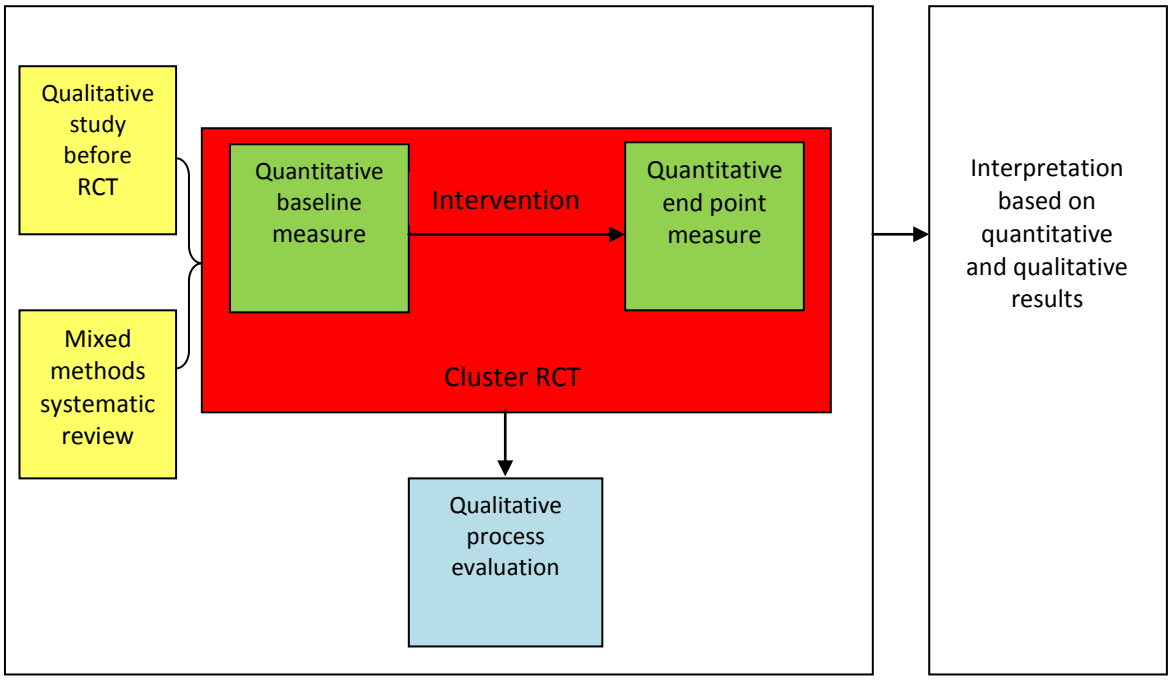


Figure 1.3: Study design

1.4.9 Implications for the thesis

There were four implications of the study epistemology and design for the thesis:

The first implication of adopting a subtle realism perspective was in the use of a mixed methods design. This allowed for the exploration of an individual's experience, alongside quantitative group-level data. The design fits well with a subtle realism perspective and was suited to health services research.

The second implication relates to the analysis within the systematic review component of the thesis (Chapter 3). A narrative synthesis was used to combine qualitative and quantitative studies. This approach to evidence synthesis was consistent with the overall mixed methods design of the study and the study epistemology.

The third implication of a subtle realism perspective was the explicit acknowledgement of my own cultural background and upbringing and how this may have influenced the research process. Reflexivity relates to the awareness of the ways in which the researcher and the research process have an impact on the data collection and analysis. In particular, reflexivity involves an awareness of one's own background, prior assumptions and experience, and how these might shape the research process [33]. Reflexive memos were used during the qualitative sections of the study to record any assumptions or interpretations. The main qualitative chapters of the thesis contain sections on reflexivity (Sections 3.3.1; 5.4 and 8.3.4).

Finally, as discussed in Section 1.4.3, the concepts of validity and relevance are important within a subtle realism perspective. Consequently, the final implication of a subtle realism perspective involved the assessment of quality throughout the thesis. In particular, the qualitative section of this thesis (Chapter 5), focuses on issues of validity and relevance in addition to reflexivity.

1.5 Contribution of the student

This thesis was conducted as part of the REFOCUS Programme. My general contribution to the REFOCUS programme was made as a member of the REFOCUS research team. This included contributing to the overall design of the programme and trial protocol, leading the development and publication of the REFOCUS Intervention, Model and Manual, recruiting teams, staff and service users into the trial, collecting data from participating teams, assisting with the development of the assessment batteries including the development of new measures, leading the data management for the cluster RCT, commenting on papers led by others in my capacity as co-author, and leading a number of REFOCUS papers. I was also responsible for setting up one of the study advisory panels, namely, the BME virtual consultation panel, whose contribution is outlined in section 1.5.1.

In addition to these general contributions, I made specific contributions which are the subject of this thesis and are outlined below chapter by chapter:

Chapter 2: The literature review was specific to the PhD, was not part of the REFOCUS programme, and was all my own work.

Chapter 3: I led the design of the systematic review, developed the review protocol, conducted the literature searches, collated and appraised the literature and worked with other REFOCUS researchers on the analysis. The analysis included a sub-group analysis of

papers focusing on minority ethnic populations. I led on the identification of papers for the sub-group analysis and conducted the qualitative analysis.

Chapter 4: The literature review was specific to the PhD and was not part of the REFOCUS programme, and was all my own work

Chapter 5: I was responsible for the addition to the planned REFOCUS study of four focus groups and 14 individual interviews with participants from black backgrounds. I developed the topic guides, recruited all the participants, conducted the interviews and focus groups and conducted the analysis.

Chapters 6: I led the overall development of the REFOCUS Intervention, Model and Manual, including publication. Specific to this thesis was Working Practice 1: Understanding Values and Treatment Preference, which built on the work presented in Chapter 5.

Chapter 7: I was responsible for the inclusion of a sub-study focused on the effectiveness of the intervention for black individuals. I conducted the power calculations for the BME sub-study and added an additional primary outcome, the CSQ-8, to the trial protocol.

Chapter 8: At baseline and follow-up I collected approximately 30% of the service user outcome data during the trial and led data management. All the analysis reported in this thesis was conducted independently. For the qualitative process evaluation I led all aspects, including conducting the eight interviews with BME participants and analysing the data.

1.5.1 BME virtual consultation panel

One of my contributions to the REFOCUS programme was the set-up and recruitment of the BME virtual consultation panel. The panel was set up to provide advice and guidance throughout the thesis. The consultation panel was made up of black individuals (self-ascribed ethnicity) with lived experience of mental health services and / or people (from any background) with expertise conducting research with individuals from black backgrounds. All communication with the virtual panel was via e-mail correspondence, with a voluntary sector organisation (Fanon) helping to support users of their service to participate in the panel. In total 12 individuals were included in the panel and had the following expertise: three people with lived experience, one user researcher, four staff members and four researchers. The information sheet including the terms of reference for the BME virtual consultation panel are included in Appendix 1. The virtual consultation panel took part in five consultations at various points within the study, which are described in Sections 3.2.4; 5.2.4; 6.2.1; 6.2.3 and 7.9.4.

Chapter 2 Mental health needs of black individuals

2.1 Introduction

Culture, race and ethnicity are known to exert an influence on the prognosis, presentation and experience of mental illness. What is considered an illness and the help-seeking process are both influenced by culture and ethnicity. Furthermore, cultural practices and beliefs create contexts in which idioms of distress are constructed, with Bhugra stating that *"culture clothes the disease, and turns it into illness"* [[10] p22]. Empirical studies investigating ethnic inequalities in mental health care have increased exponentially in the last two decades, with a wealth of studies assessing different aspects of minority mental health [54].

This chapter aimed to review the literature regarding the mental health needs and inequalities experienced by black individuals in the UK. Given the large amount of research on this topic, this chapter focuses on key ethnic inequalities which provide contextual information useful for this thesis, and provided part of the rationale for focusing on the recovery of black individuals. Four inequalities are described: i) the increased incidence of mental health problems, ii) complex and adverse pathways to care iii) use of MHA and iv) outcomes and experience of care. The chapter will then briefly present a summary of mental health policy in relation to race, culture and ethnicity, before discussing the implications for the thesis.

2.2 Incidence of mental health problems

2.2.1 Psychosis

Since the 1960s over 20 studies have demonstrated an increased rate of psychosis in minority groups living in the UK. However, despite consistent evidence for an increased rate of psychosis, earlier studies included methodological limitations. These limitations included the use of broad racial categories, which did not take into account different cultural and ethnic groups and diagnosis conducted by psychiatrists who were not blinded to the ethnicity of the person.

The AESOP study, an incidence survey conducted across England, aimed to overcome the methodological limitations of previous research. The study utilised a case-control design to assess the incidence rates of psychosis within different ethnic groups [55]. The initial findings indicated that all minority ethnic groups had increased rates of schizophrenia and related disorders when compared to the white British group. In particular, incidence rates for males of black Caribbean and black African ethnicity were notably raised (IRR = 5.6, 95%CI: 4.2-7.5

and IRR = 4.0, 95%CI: 2.9-5.7, respectively). Furthermore, incidence rates were raised in all minority ethnic groups even after factors such as age, gender, study site and social deprivation were adjusted for [17,55,56]. The findings of the AESOP study have been replicated by the East-London First Episode Psychosis study, which demonstrated an increased rate of non-affective psychosis, particularly in black African and black Caribbean individuals compared to the white British population (IRR = 2.7, 95%CI: 1.5-4.9 and IRR = 4.0; 95%CI: 2.4-6.9, respectively) [57]. Taken together, the East-London First Episode Psychosis Study and AESOP represent over 40% of the population in London [58].

The findings of the two London studies have been corroborated by a recent systematic review and meta-analysis of papers published between 1950 and 2009 which assessed the incidence of schizophrenia in England [18]. Consistent with the above, the pooled incidence rates indicated that individuals from black Caribbean and black African backgrounds were at evaluated risk of most forms of psychosis most notably schizophrenia. The elevated rates reported could not be explained by age or gender differences between the ethnic groups and were present for first and second generation immigrants, suggesting the increased risk was not wholly explained by selective immigration [18].

2.2.2 Other mental health disorders

Although much of the research has focused on psychosis, empirical investigations have assessed differences in the incidence and prevalence of other mental health problems, including common mental disorders, self-harm and personality disorders. The EMPIRIC study compared the prevalence of anxiety and depression amongst a representative sample of individuals from six different ethnic groups, including individuals from black Caribbean backgrounds. Although there were some significant differences in prevalence rates between the different ethnic groups, these differences were modest [59].

With regards to self-harm, a number of population-based studies have been conducted within the UK to compare the rates and risk factors between different ethnic groups. A systematic review of rates and methods of self-harm identified 25 UK publications [60]. Although the majority of research focused on individuals from South Asian backgrounds, the limited data available did indicate that individuals of Caribbean origin may be at increased risk of self-harm [60]. The review findings were corroborated by a prospective cohort study of cases of self-harm which indicated that young black women had the highest rates of self-harm. Furthermore, young black women were more likely to self-harm if they were unemployed and

experienced housing difficulties. However, despite this increased risk, young black women were less likely to receive psychiatric care [61,62].

Finally, a systematic review and meta-analysis including seven studies which assessed prevalence, aetiology and treatment of personality disorder found that rates of personality disorder were over two times lower for black individuals compared to the white British population [63]. Furthermore, removal of the US studies reduced the odds ratio of black individuals being diagnosed with personality disorder compared to white individuals even further, a finding consistent with service-based research indicating that black individuals have lower rates of personality disorder [64] and were less likely to be referred for specialist treatment [65].

In summary, the literature suggests that black individuals have a higher rate of psychosis, most notably schizophrenia compared to other ethnic groups. Although less researched, there is some evidence of ethnic differences in the prevalence and incidence of other mental health problems including common mental disorders, self-harm and personality disorder.

2.3 Explanations for increased incidence rates

Although research has established increased rates of mental health problems, there is less certainty regarding the factors underlying this increased risk. Numerous hypotheses have been formulated to explain these ethnic differences, ranging from biological to cultural explanations. It is beyond the scope of this thesis to review all proposed explanatory factors. Instead, the review will focus on three key areas: i) the experience of racism and racial discrimination, ii) the impact of migration and iii) social factors.

2.3.1 Experience of racism and racial/ ethnic discrimination

Back in the 1980s Littlewood and Lipsedge published their influential book focusing on the psychological consequences of migration, suggesting that mental illness was a response to disadvantage and prejudice [54]. This section specifically focuses on racial prejudice and discrimination, including institutional racism as an explanation for the increased incidence rates of mental ill health amongst individuals from black backgrounds.

Institutional racism

In 2007 a series of publications ignited the debate about institutional racism within mental health services. Institutional racism refers to an organisation's failure to provide appropriate

and professional services to individuals because of their race, culture or ethnicity. By definition, institutional racism is not directed at the individual clinician and their clinical encounters with service users (although this does not preclude the existence of interpersonal racism). Instead, institutional racism relates to the whole system [54]. In particular, institutional racism can be detected in the organisation's processes, attitudes and behaviours which according to the MacPherson report *"amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantages people in ethnic minority groups"* [[15] p18].

One proposed reason for the increased incidence rates is that institutional racism results in the misdiagnosis of people from black backgrounds [66]. Although institutional racism has been cited as a primary reason for the over-representation of black individuals within involuntary care (discussed in section 2.50), the poorer engagement of black communities and the lack of treatment options offered within mental health services (see section 2.7), research has not directly supported the role of institutional racism in terms of misdiagnosis. For example, the AESOP [55] and the East London First Episode Study [57] reviewed above, both based diagnosis on case notes in which the psychiatrists were blind to the race, culture and ethnicity.

However, Fernando argues that institutional racism does not merely lie with misdiagnosis, but is evident in the practice and application of Western psychiatry to all cultures and settings [11]. Linked to this suggestion is the concept of cultural relativity, such that that features of schizophrenia may overlap with cultural features common in non-western cultures [67]. For example, the classification of religious experience may differ within Western and non-Western cultures. This argument suggests that institutional racism lies in the history, beliefs and practices of psychiatry, such that psychiatric diagnoses are socially constructed categories, serving a social purpose. According to Fernando, standardised assessment processes fail to take into account the complex social, cultural and political factors and instead reduce this complexity to a diagnostic label [11].

Interpersonal racism

In contrast to institutional racism, interpersonal racism focuses on racism and discrimination at the individual level. A cross-sectional nationally representative community survey (EMPIRIC) indicated that racism was related to both increased risk of common mental health disorders and symptoms of psychosis. Within the survey, 36% of individuals from black

Caribbean backgrounds reported experiencing racism. Furthermore, the results suggested that experiencing interpersonal racism, and perceiving society to be racist were independently associated with increased risks of mental health problems. Furthermore, controlling for the impact of social support within the analysis did not change the results, suggesting that racism was independently associated with negative mental health outcomes [68].

These findings have been further substantiated by qualitative studies. For instance, when interviewed, black Caribbean and white British individuals with psychosis reported a similar number of episodes of discrimination or unfair treatment. However, Black individuals were more likely to attribute this unfair treatment to racism, instead of mental health stigma, which was the main explanation given by the white British participants. Furthermore, individuals from black backgrounds were more likely to believe their distress and mental health problems were due to racial discrimination [69].

2.3.2 Migration stress and selective migration

The second set of explanatory factors relate to the migration experience. Rates of psychosis have been shown to be elevated in migrant populations as opposed to indigenous populations, across different countries [17]. For example, the rates of psychotic illness in black Caribbean people in the UK are elevated compared to the white majority population, whereas the rates for black Caribbean people living in Trinidad are comparable to the UK majority population [70]. Furthermore the evidence reviewed in Section 2.2 highlighted how the increased risk of mental health problems extended to all minority ethnic groups, including white minority populations (e.g.[2]). This suggests that there are factors associated with minority status that go beyond ethnicity, race, or skin colour.

One explanation for the increased rates in immigrants compared to indigenous populations relates to selective immigration whereby mental illness may predispose people to migrate [54]. However, this hypothesis has not been supported by studies assessing the rates of illness within both second generation and third generation immigrants, which indicate a lack of generational effects [18].

A second explanation for the increased incidence rates in migrant populations is that of migration stress, which relates to both the experience of migration as a direct stressor and to the post-migratory experience, including chronic stress and disadvantage [71]. Although migration can be a stressful event, the experience of migration is likely to be varied. For

example, individuals who voluntarily move to another country may have a different experience to refugees forced to leave. Consistent with this, significant variation has been highlighted for different ethnic groups, although it must be noted that ethnicity is a poor proxy for migration status [56].

A recent systematic review and meta-analysis indicated that where migration was associated with downward social mobility, individuals were more likely to screen positive for mental health problems [72]. Furthermore, a mixed methods study of Somali immigrants highlighted how migration was associated with unemployment, and devalued identity. These negative experiences coupled with a longer stay in the host country were associated with mental illness and poorer wellbeing [73].

2.3.3 Social factors

An emerging evidence base suggests social factors including ethnic density, [74], urbanicity and urban birth [67], social adversity [75], early parental separation [76] and stressful life events [77] all have a negative impact on mental health. This evidence basis is now selectively reviewed with particular attention paid to ethnic density, unemployment, social disadvantage/adversity and perceptions of disadvantage.

Ethnic density

The impact of racial discrimination and racism previously discussed may be more pronounced for individuals who live in areas where the number of people from minority ethnic backgrounds is lowest relative to the total population. This has been termed the ethnic density hypothesis with the negative relationship between relative size and incidence rates linked to factors such as overt discrimination, feelings of alienation and cultural incongruity [10].

Despite some support for this hypothesis from non-UK based studies research in the UK has been mixed [74]. A narrative review of UK studies assessing the ethnic density hypothesis provided mixed findings for both common mental health disorders and psychosis. Four papers included in the review assessed the impact of ethnic density on rates of depression and anxiety for black people in the UK. One study indicated that ethnic density was protective, with the other three studies producing neutral results. For psychosis, five UK studies were included. Ethnic density overall was a protective factor, however, when looking at ethnic density for the different ethnic groups e.g. black African, black Caribbean, the results were

neutral [74]. One explanation for these contradictory results relates to ethnic separation. This hypothesis suggests that it is not only the absolute number of people from a particular ethnic group, but how dispersed people are within a given area. For example, an area may have a relatively high number of individuals from a particular ethnic group who are spread out compared to an area where a smaller number of individuals reside in one small area [78].

Unemployment

Unemployment has been shown to be a risk factor for the development of psychosis regardless of ethnicity [70]. However, unemployment rates are particularly high for individuals from minority ethnic backgrounds. Unemployment following migration was associated with increased rates of mental health problems within Somali individuals in the UK [73,79], and within a systematic review and meta-analysis [72]. Furthermore, the meta-analysis indicated that underemployment was also an important factor in the development of mental health problems. Underemployment refers to individuals who had previously held a higher socioeconomic position within the country of origin, compared to their socioeconomic position within the host country [72]. Consistent with this finding, Somali individuals from a professional background reported more negative post-migratory experiences including culture shock, unmet expectations of living conditions and a devalued identity [73].

Socioeconomic disadvantage and adversity

As with unemployment, socioeconomic adversity and deprivation have been indicated as factors in the development of psychosis regardless of ethnicity [80]. However, evidence indicates that individuals from black communities are more likely to experience socioeconomic disadvantage compared to the white British population [81]. In all studies, socioeconomic adversity was linked to increased rates of mental health problems for black individuals [58,82,83].

However, socioeconomic status alone cannot wholly explain the elevated risk demonstrated for black individuals. Consequently, one suggestion for the increased incidence rates evident is that minority groups, particularly black African and black Caribbean, may experience a greater distribution of several negative social and environmental factors. Bhugra notes that ethnicity was associated with a number of social factors, including unemployment, lone parent status, lower social class, low perceived social support, and poverty. Even though these associations were common in all ethnic minorities, there was only an association for every factor in the

black Africans and African-Caribbean groups, suggesting that they may be more prone to a combination of risk factors [10].

Perception of disadvantage

One theory linked to the above suggests that in additional to *actual* social disadvantage, the *perception* of disadvantage may be a risk factor for the development of mental health problems [84,85,86]. Cooper and colleagues investigated perceptions of disadvantage in people from black ethnic groups both with and without psychosis [86]. Perceptions of disadvantage and rates of psychosis were greater for black individuals compared to white British individuals, with socio-economic disadvantage and perceived disadvantage associated with an increased risk of psychosis. Black individuals with psychosis were less likely to include racism as an explanation for disadvantage. Instead, perceptions of disadvantage were linked to a range of factors including lack of social support, bad luck or physical appearance. Furthermore, social factors, religious affiliation and unemployment all had an impact on incidence rates, independent of perceptions of disadvantage, suggesting a complex interaction of factors [86].

A further study tested whether identifying with socially disadvantaged minority groups was associated with increased rates of mental health problems [87]. Using data from the AESOP study, the analysis tested whether ethnic identity was independently associated with an increased risk of psychosis, after controlling for perceptions of disadvantage. The results indicated that although attenuated by perceptions of disadvantage, strong ethnic identification for BME individuals, but not white British individuals, increased the risk of psychosis [87].

2.3.4 Summary of factors

The emerging picture regarding the reasons for the increased incidence of mental illness is complex, suggesting an interaction between multiple social, cultural, and ethnic factors which impact at an individual, neighbourhood and population level. Risk factors for the development of psychosis, such as unemployment, social isolation, social adversity and other markers of disadvantage appear to be more common for people from black African and black Caribbean backgrounds, where the incidence rate of psychosis is greatest. Any interventions aimed at improving the recovery of black individuals, need to be mindful of this literature.

2.4 Pathways to care

The next section focuses on evidence for inequalities in the pathways to care and rates of involuntary admission, before discussing the reasons for these two inequalities.

A systematic review assessing ethnic variations in the pathways to specialist mental healthcare demonstrated five main areas of concern [19]. These comprised differential rates of detection and referral for mental health problems, more complex pathways to mental health services often involving forensic services, poorer engagement and continuity of care, increased inpatient use and higher rates of involuntary admission. The review highlighted that although all minority ethnic groups were at risk of experiencing health inequalities, this risk was greatest for black individuals. With specific reference to the pathways into care, individuals from black communities were more likely to have complex routes into specialist mental health services. This included involvement with the CJS, as well as an increased number of contacts with helping agencies prior to contact with secondary care services [19].

Following the review, numerous studies have assessed the different routes into specialist services for black individuals. One consistent finding has been the more complex pathway to care experienced by black individuals and in particular the involvement of the CJS [76,88]. For example, Ghali and colleagues demonstrated a five-fold increase in the risk of CJS involvement for black service users [88].

A recent systematic review assessed the differences in pathways to care for individuals experiencing a first episode of psychosis [20]. The review focused on ethnic differences in GP involvement, police involvement and involuntary admission. Seven studies were included in the review, including five from the UK. Results of the pooled analysis indicated that relative to white individuals, black people were significantly less likely to have GP involvement (OR = 0.7, 95%CI, 0.57 - 0.86) but were twice as likely to have police or CJS involvement in their pathway to care (OR = 2.05, 95%CI, 1.63 - 2.59). These findings have been further substantiated by a systematic review focusing on the UK-only literature, which indicated that BME individuals had increased rates of CJS involvement and lower rates of GP involvement when coming into contact with specialist mental health services [3].

Despite these consistent findings regarding first episode psychosis, a more recent study conducted by Bhugra and colleagues investigated differences in pathways to care amongst individuals within forensic mental health settings, and failed to find any differences between

ethnic groups (cited in [54]). The pathways reported in the study were broadly similar for all ethnic groups. Based on these findings, the authors suggested that the lack of difference demonstrated in this study may reflect a shift in practice, including a greater awareness of issues pertaining to race and culture. However, further replication of this finding is required.

2.5 Use of the MHA, involuntary admissions and CTOs

Individuals from black communities are also disproportionately detained under the MHA. A systematic review and meta-analysis indicated that individuals from black backgrounds were 3.83 times more likely to be detained than white British individuals with an over-representation of black individuals for both civil and forensic detentions [4]. Subsequent studies published since the review have substantiated these findings [82]. Furthermore, three reviews including UK-based studies have focused on the first episode of psychosis, highlighting that ethnic differences in use of the MHA are apparent from the first contact with services [3,20,22].

However a recent prospective study which assessed data collected for all MHA assessments within three areas of the UK over a four year period from 2008 - 2011 produced contradictory findings [89]. The analysis indicated that low levels of social support, being in London, being female, having a diagnosis of psychosis and presenting with elevated risk were all independently associated with increased risk of involuntary admission. Although there were ethnic differences in the distribution of the identified risk factors for involuntary admission, ethnicity was not an independent predictor [89].

Finally, results from the Count Me In Survey of inpatient experience indicated that individuals from all BME backgrounds were over-represented in terms of the number of people on community treatment orders (CTOs), with black individuals more likely to be deemed incapable of consent compared to white individuals [7].

2.6 Explanations for adverse pathways to care including increased use of the MHA

Singh has proposed four interrelated reasons for differences in pathways to care. These are i) clinical factors which relate to the presentation of symptoms and manifestation of behaviours during the first episode, ii) delay in help-seeking, iii) social factors including social networks

and social contacts and iv) illness recognition and attribution [3]. Each of these explanations will now be considered.

Firstly, the clinical presentation and behaviours associated with the illness may vary between ethnic groups. Bhugra and colleagues have suggested that individuals from black backgrounds are likely to present with a more acute presentation compared to an insidious onset for white British individuals [70]. In particular, research has suggested that individuals from black backgrounds were more likely to show self neglect, and are perceived by staff as more dangerous, with heightened levels of agitation compared to their white counterparts [70].

The second explanation relates to a delay in help-seeking for black individuals. Oluwatayo and Gater investigated the reasons for increased rates of compulsory admission for black individuals and suggested that poor engagement with primary care and mental health services was a contributory factor [90]. This was further suggested by Bhugra who highlighted that black individuals were less satisfied with primary care services compared to white participants [91].

The perception of mental health services has also been linked to a delay in help-seeking. The Breaking the Circles of Fear report utilised a participatory approach and collected data via different methods including a national call for evidence and focus groups with staff, service users, carers and other statutory agencies including the police [81]. The main finding within the report was the existence of a circle of fear. Individuals from black backgrounds were often fearful of services and saw them as coercive and oppressive. This was coupled with a general fear of mental health problems within the community including mental health stigma. As a consequence black individuals reported coming into contact with services at a later stage, and often in crisis, where more coercive and restrictive treatments such as compulsory admission were required. This pathway to treatment often involved the police and reinforced the view of mental health services as coercive and oppressive hence perpetuating the circle of fear [81]. However, despite the proposed delay in help-seeking, there is at present no substantial and consistent evidence that black individuals have a longer duration of either untreated psychosis or illness [3].

The third explanation for the adverse pathways to care relates to social factors which have an impact on the presentation of illness. Evidence suggests that those who are more socially isolated may experience a lack of external stimulation thus leading to a loss of self-interest

and self-neglect. A systematic review into social networks and social support in early psychosis found that individuals with psychosis had a lower level of social support and fewer contacts than the general population [92]. Furthermore, this reduction in social support pre-dated the development of psychotic symptoms Currently, research assessing differences in social support between ethnic groups is limited although there is a trend suggesting that individuals from BME backgrounds may be more socially isolated.

The fourth explanation is that there are differences in explanatory models of illness between black and white individuals which may influence illness recognition. There is a wealth of research into variations in the explanatory models of illness across different ethnic and cultural groups. For example, in a study comparing the explanatory models of individuals from different ethnic groups, people from black background were less likely to adopt biological explanations and more likely to attribute mental illness to social or spiritual factors compared to white participants [93]. Furthermore, explanatory models had an impact on client satisfaction and the therapeutic relationship with individuals who held biological explanatory models, more likely to seek psychiatric help and be satisfied with treatment.

Finally, in addition to the four explanations above, institutional racism has been cited as one explanation for the increased use of the MHA for black individuals [94]. An alternative suggestion is that differences in illness presentation are due to racial stereotypes with black individuals perceived to be more dangerous by staff, compared to white individuals. This in turn leads to the use of more coercive measures and increased use of the MHA [81].

2.7 Satisfaction and experience of care

The experience and satisfaction with different mental health services has received less attention, despite being cited as a central component of a person's recovery [95]. A number of studies have focused on the course and outcome of psychosis. A review into UK-based research identified 14 studies which assessed outcomes by ethnicity [96]. The studies were predominantly poor in quality and subject to a range of methodological limitations such as retrospective data collection, small sample sizes and broad ethnic and racial categorisation often based on proxy measures. Results of the review indicated that there was little difference in course and outcome across ethnic groups for a range of outcomes including contact with services and symptom levels. Where there was evidence of ethnic differences, it was often inconsistent and inconclusive.

The Breaking the Circles of Fear report discussed in section 2.6 investigated the experiences and perceptions of mental health services for individual from black communities [81]. The report highlighted a general mistrust of mental health services. In particular, acute services were experienced as negative and traumatic, with the treatment options offered such as medication seen as damaging. Individuals also perceived staff as difficult to engage with, with members of the community describing staff and services as intrusive. Issues of power differentials, coercion and fear were seen as reflective of the wider experience of black people within society.

The themes identified in the Breaking the Circles of Fear report were replicated in a recent qualitative investigation into ethnic inequalities within mental health care conducted by the National Survivor User Network (NSUN). Individuals within the study talked about the impact of race, culture and ethnicity including the issue of cultural misunderstanding [97].

Furthermore, within two qualitative studies, it was noted that in general, all the service users, regardless of ethnicity, highlighted many negative aspects of inpatient care including loss of control and feelings of isolation [98,99]. However, language issues, and the experience of services as socially isolating and culturally inappropriate contributed to the negative experience of black individuals. In particular, individuals highlighted misdiagnosis of cultural features and misinterpretation of self-expression as prevalent experiences within care [99].

One consistent finding across all the different research studies has been a lack of satisfaction with the treatment options offered. Although Rayleigh and colleagues failed to find any difference in overall levels of satisfaction between black and white British individuals, black people were less satisfied with their access to talking therapies [100]. These findings were further supported by the AESOP study, which demonstrated that individuals from black backgrounds were less satisfied with certain elements of the treatments they received [5]. In particular, black Caribbean service users were less satisfied with the admission process and did not believe they were given the right treatment. Consistent with this, 77% of individuals who took part in the NSUN study believed that their background, including race, ethnicity and culture had an impact on the support they received, including access to psychological therapies and an overreliance on medication [97].

2.8 Mental health policy

The literature review will now briefly consider policy in relation to ethnicity race and culture as well as cultural competency within mental health services.

2.8.1 Mental health policies relating to ethnicity, race and culture

Since the early 1990s mental health policy has varyingly included issues pertaining to race, culture and ethnicity. The main mental health policies within England in the last 10 years, including historical events pivotal to the development of policy are shown in Table 2.1 (adapted from [101]). Policy documents in bold, are then briefly summarised.

Table 2.1: Key mental health policies in England between 1994 - 2011

Year	Mental Health Policy or Document
1994	Black Mental Health: A Dialogue for Change
1994	Mental Health Task Force: London Project and Regional Race Programmes
1994	NHS Executive Newsletter EL994/77: Collection of Ethnic Group Data for Admissions
1995	Mental Health: Towards a Better Understanding
1999	National Service Framework
2000	NHS Executive Plan
2000	The Race Relations (Amendment) Act 2000
2003	Inside Outside: Improving Mental Health Services for BME Communities in England
2003	**Delivering Race Equality (DRE): A Framework for Action**
2003	Inquiry into the Death of David Bennett
2005	**DRE: An Action Plan for Reform Inside and Outside Services and Responses to Inquiry into the Death of David Bennett**
2007	Challenges to Institutional Racism and Dashboard
2009	New Horizons, Social Inclusion, Mental Capacity and Wellbeing
2010	The Equality Act 2010
2011	**No Health Without Mental Health**
2011	The Equality Delivery System (EDS)

2.8.2 Delivering Race Equality

Delivering Race Equality (DRE) was a major policy framework published in 2005 which directly responded to the inquiry into the death of David Bennett. DRE was a five-year plan guided by the principles of race equality with the overall aim of improving services for all people from BME communities. In particular, the action plan was designed to reduce inequalities in access, experience and outcomes relating to mental health care [102].

Three main aims were included and corresponded to i) better information, ii) community engagement and iii) more appropriate and responsive services [102]. To achieve the aims, DRE

set out an action plan for a five year period covering 2005 - 2009. This included 78 actions to help organisations reach the aims of the report, for example, cultural capability frameworks and monitoring outcomes for individuals from BME backgrounds [9,102].

A review of DRE conducted for the Department of Health indicated that although local and national efforts had been made to achieve the aims of the framework, they had not resulted in significant change for black individuals [103]. However, the review did highlight areas of success and good practice including the implementation of Race Equality Leads, the employment of community development workers and the development of performance indicators to enable future review.

DRE has since been replaced by mental health policy, including 'No Health without Mental Health' which aim to improve care for all groups [104].

2.8.3 No Health without Mental Health

The latest mental health policy within England launched by the Department of Health in 2011, *'No Health without Mental Health'* stresses that mental health is everyone's business and not just relevant to individuals with mental health problems [105]. Good mental health and resilience is seen as fundamental to other areas of life, including physical health, education, employment, relationships and to the economy. The strategy is seen as more than just a service plan and aims instead to promote the transformation of the mental health system as well as transform public attitudes towards mental health.

Two main aims are included in the strategy. These can be summarised as i) improving the mental health and wellbeing of the whole population and ii) providing high-quality services to improve the outcomes for the people who use them. Six objectives are included in the strategy to achieve the two aims. These are:

1) More people will have good mental health,
2) More people with mental health problems will recover,
3) More people with mental health problems will have good physical health
4) More people will have a positive experience of care and support
5) Fewer people will suffer avoidable harm and
6) Fewer people will experience stigma and discrimination.

Although not specifically focusing on BME individuals, the strategy considers inequality with reference to 'protected characteristics', including gender, age and ethnicity. The strategy recognises the negative impact that societal stigma can have on all people with mental health problems, it highlights how not all groups of individuals have benefited equally from past service improvements. Disparities in access to services and treatments as well as poorer outcomes, including compulsion and involuntary detection are highlighted as problem areas to target [105].

2.8.4 Cultural competency and cultural consultation models

The cultural capability of staff was one area explicitly mentioned within DRE and is a potential target for any service or intervention aiming to improve recovery. To improve the cultural capability of staff, cultural competency training was proposed [101,106]. However, despite increased use of the term within policy documents, it has been poorly defined, with limited attention to what cultural competence would mean for staff and individuals. Despite this ambiguity in definition, features common across different cultural competency programmes include i) a focus on interpersonal communication, ii) developing effective working relationships, iii) maximising sensitivity, iv) increasing knowledge, values and skills of staff and v) promoting self-awareness, all within the context of culturally diverse communities and interactions [107].

A systematic review aimed to identify definitions and models of cultural competency within mental health care, and to assess the effectiveness of cultural competency [108]. Although nine papers were included, none were from the UK. Papers within the review varied as to whether they focused on front-line clinical staff, medical students or organisational aspects of cultural competency, and differed in their definitions of cultural competence. Despite some positive findings including intended and actual behaviour change following cultural competence training, none of the studies evaluated service user outcomes [108].

Consistent with the above review, a report conducted by the Sainsbury Centre for Mental Health noted that the delivery of cultural competency training within the UK was patchy and rarely evaluated [106]. The report further highlighted how a *'One size fits all'* approach to race relations training did not adequately address the issues raised by BME service users. Furthermore, even where there was evidence of improved cultural knowledge amongst staff, this did not always translate into improvements in the experience and outcomes of individuals using the service [106].

More recently, it has been suggested that to better achieve the aims relating to race equality within a multicultural society, there should be a move away from cultural competence to instead focus on cultural consultation [109]. Cultural consultation as an approach focuses on different narratives of the individual, the clinical staff and the organisation. The approach is informed by anthropology and ethnographic methods. Evaluation of a service within a culturally diverse region of East London, indicated that the dominant narratives within operation prioritised the organisation at the expense of a truly individualised service. Furthermore, the issue of culture was seen as only an attribute of minority ethnic service users, with staff failing to acknowledge the role of their own culture within the consultation [109].

2.9 Implications for the thesis

This chapter has provided the background information on the mental health needs of black individuals within the UK, and outlined the policy relating to race, culture and ethnicity. The chapter highlighted the context in which any intervention aiming to improve the recovery of black individuals is conducted. Findings from the literature review have five theoretical and one methodological implication for the remainder of the thesis.

Firstly, the literature review provides the rationale for focusing on the experience of recovery for black individuals. Individuals from black communities face a number of inequalities in terms of mental health needs and care. The increased rates of mental health problems, more complex pathways to care and CJS involvement point to a negative picture of the experience of black individuals. Not only is this negative experience important in its own right, it is also likely to shape clinical encounters including staff and service user interactions. Furthermore, the evidence suggesting overrepresentation and misdiagnosis (whether perceived, actual or both) influence how black individuals respond to mental health services.

Secondly, the review provided the rationale for developing a pro-recovery intervention focused on clinician and service user interactions and the working relationship. The review highlighted that satisfaction with care and the treatment options offered were particular problems for individuals from black communities. Furthermore, the public perception of services as fearful is likely to impact on the whole care process, including the therapeutic relationship. Equally, the potentially more acute onset, self-neglect and the known dissatisfaction with services is likely to impact on clinicians and their approach to individuals

using services. Given both these service user and clinician negative preconceptions, a recovery orientation which explicitly focuses on the relationship between individuals may be one way of improving the experience of care.

Thirdly, the literature indicated that the personal experience of racism was an important factor to further investigate during the qualitative study conducted as part of this thesis. The experience and perception of racism has been implicated in the increased prevalence rates, more complex pathways to care and poorer experience of services. The experience of racism within services and the suggestions of institutional racism provide the context in which staff and service user interactions occur. However, there is evidence that within services such issues are not discussed.

Fourthly, the evidence that individuals from black communities within the UK experience multiple social risk factors for mental health problems such as unemployment, racism, discrimination and poverty suggested that any intervention aiming to improve recovery would need to take a wider perspective to understand the social context. This theoretical implication suggested that the impact of these multiple social adversities needed to be considered to understand the perspective of black people using services.

The fifth theoretical implication concerns the move towards cultural consultancy and away from cultural capability training. This highlights the importance of the individual's narrative as well as the narratives of staff and the organisation, including understanding how culture and ethnicity apply to everyone, including staff and mental health services. One implication of this was that the intervention should help staff support the individual to develop a narrative, which may or may not include services. Furthermore, staff using the intervention were encouraged to develop their own narratives and to consider their own values surrounding race, culture and ethnicity.

Finally, one methodological implication arising from the literature review was that the evidence provided a rationale for using a wide inclusion criteria for the sub-group analysis within the cluster RCT. The literature indicated that the increased rates of mental health problems and poor experience of care are issues for a wide range of black ethnicities, including people who self-ascribe their ethnicity as black African, black Caribbean or black British. Inequalities in mental health care were not restricted to one particular ethnicity such as black African.

Chapter 3 Systematic review and narrative synthesis of the meaning of recovery for black individuals.

3.1 Introduction

As suggested by the MRC framework, prior to developing an intervention, there is first a need to understand and define the meaning of terms and concepts central to the intervention for the target population [31]. This chapter presents a systematic review and narrative synthesis of the meaning of personal recovery for people from black backgrounds. The wider review, conducted as part of the REFOCUS Programme is presented with an in-depth focus on the sub-group of papers specific to this thesis. The conceptual review has been published in two papers [110,111] which are included in Appendix 2.

3.1.1 Historical development the meaning of recovery

The development and use of the term recovery can be traced back to three different perspectives, namely 1) survivor movements, 2) rehabilitation and social psychiatry and 3) biomedical approaches to mental illness [112,113]. The three different perspectives are briefly outlined below.

Many ideas concerning recovery relate back to the 'psychiatric survivor' movements in the early 1970s [114,115,116]. In this context, individuals with lived experience of the mental health system demonstrated that they can and should have a life beyond their symptoms and being a patient. Regardless of an individual's definition of recovery, advocates stressed the need for a meaningful life, whether or not symptoms were present. This included a focus on living a safe, dignified and satisfying life often within the presence of on-going adversity including discrimination and marginalisation. Davidson terms this 'recovery in' and notes how the concept has its origins in the self-help movements typified by the addictions field [114]. Central to this philosophy was the notion that recovery involves overcoming the effects of mental illness including loss of social roles, social isolation and the negative impact of involuntary hospitalisation. Akin to the Civil Rights Movement, recovery is seen as a social process, particularly where individuals face many barriers to becoming an empowered citizen [112,117,118]. This definition and origin of recovery, has been termed ‘personal recovery’ [25].

Alongside the service-user/survivor movement, recovery was also being championed and to a certain extent modelled on a social psychiatry movement with rehabilitation at the core. The emphasis within this approach is placed on providing people with life skills in a supportive environment to enable them to stay out of hospital, manage their illness, function day-to-day and integrate within society [112]. The presence or absence of symptoms was seen as less important than functioning and enhancing the person's resources and abilities. Recovery in this sense, involved living a full-life and returning to 'normal functioning' as far as was possible.

Finally, the third origin of the word recovery relates to the notion of clinical recovery, which is often linked to a biomedical view of mental illness [118]. Proponents of this perspective see mental illness as something 'inside' the person which is diagnosable based on set criteria. Mental illness is given a biomedical definition and the aim of services is to treat the illness. Biomedical approaches stress the need for evidence-based interventions that aim to reduce symptoms and 'cure' the person who is seen as a patient [112,113]. Lieberman proposed criteria for clinical recovery from schizophrenia which included remission of symptoms, engagement in activities such as occupation and education, independence, cordial family relations, recreational activities and satisfying peer relationships [119]. Aside from a focus on symptom reduction, there is a consistent focus on risk management. Policy relating to this definition of recovery foregrounds efficacious interventions and strategies.

In summary, the three uses of the term recovery focus on 1) recovery from the effects of mental illness by prioritising living a meaningful empowered life (personal recovery), 2) recovery from impairment by prioritising successful rehabilitation and integration (social rehabilitation) and 3) treatment aimed at symptom amelioration (clinical recovery). At an individual level, recovery may include any or all of the above three definitions [113]. This thesis is primarily concerned with the first use of the term recovery.

3.1.2 Rationale for the review

One of the common criticisms of the recovery movement has been the absence of a scientific evidence base [120]. Although definitions of personal recovery stress the unique and personal nature of the journey, this is seen as incongruent with evidence-based practice where there is a need to operationalise terms and define the outcomes of interest [119,121]. The drive towards evidence-based practice within the NHS has increased the necessity for the recovery movement to adopt more rigorous and transparent methodologies, including RCT evidence.

Consequently, within an RCT, there is a need to define and operationalise the terms under investigation. This need for a definition is also consistent with the MRC framework [31].

In addition to the lack of empirical evidence base, the literature defining and conceptualising recovery is predominantly based on research with majority populations. The impact of race, culture and ethnicity has largely been ignored, with the perspectives of minority ethnic groups, including black individuals absent from the current knowledge base [28,29]. Understanding whether mainstream conceptualisations of recovery are consistent with the perceptions of people from minority ethnic backgrounds, including black individuals, is of pivotal importance when planning services and interventions aiming to promote recovery.

One way to address the above evidence gap is through the creation of a Conceptual Framework of Recovery, which defines and operationalises the term. Jabareen defines a Conceptual Framework *as "a network, or 'a plane', of interlinked concepts that together provide a comprehensive understanding of phenomenon or phenomena"* ([122] p49). The aim of this chapter was to develop a Conceptual Framework of the meaning of recovery from the perspective of black individuals.

3.1.3 Review objectives

To achieve the overall aim of the review, two objectives were included:

Objective 1: What are the overarching themes of personal recovery from mental illness?

Objective 2: Are there any characteristics or themes of personal recovery that are specific to black individuals?

3.2 Method

3.2.1 Search strategy and data sources

A systematic literature search for papers describing models, theories or frameworks of personal recovery in the area of mental health was conducted. Due to the complexity of the search and the nature of indexing qualitative articles, a two-stage cascading approach was adopted which involved an initial search followed by a second modified search. Five data sources were used:

1. The 12 bibliographic databases detailed in Table 3.1, were searched from inception to September 2009 using the following terms identified from the title, abstract, key words or medical subject headings (MeSH): ('mental health' OR 'mental illness$' OR 'mental

disorder' OR mental disease' OR 'mental problem') AND 'recover$' AND ('theor$', OR 'framework', OR 'model', OR 'dimension', OR 'paradigm' OR 'concept$'). The search was adapted for the individual databases and interfaces.

Table 3.1: Electronic databases searched

OVID	EBSCOhost	CSA Illumina
Applied and Complimentary Medicine Database (AMED) British Nursing Index EMBASE MEDLINE PsycINFO Social Science Policy	CINAHL International Bibliography of Social Science	Applied Social Science Index and Abstracts (ASSIA) British Humanities Index, Sociological Abstracts and Social Services abstracts

2. Hand searching the reference list of retrieved articles, and existing literature reviews of personal recovery [123,124,125,126,127,128,129].

3. Searching the tables of contents of relevant journals comprising Psychiatric Rehabilitation Journal, British Journal of Psychiatry, Journal of Positive Psychology, Psychiatric Services, American Journal of Psychiatry and the Australian and New Zealand ejournal of Mental Health.

4. Searching the internet via Google Scholar (scholar.google.com), NHS evidence (www.evidence.nhs.uk) and Scopus (www.scopus.com).

5. Suggestions made by the REFOCUS expert panels. The panels were the International Advisory Board (IAB) comprising international experts in the field of recovery, the Lived Experience Advisory Panel (LEAP), who were all experts by experience, the BME virtual consultation panel (discussed in section 1.5.1) and the steering group which included people with lived experience of mental health service use, service user researchers, mental health practitioners and international academics in the recovery field. In total, the groups comprised of 53 members.

The sensitivity of the stage 1 electronic search was tested by assessing whether the references retrieved from the search included ten pre-selected marker papers [130,131,132,133,134,135,136,137,138,139]. The marker papers were selected by the REFOCUS research team based on number of times cited and recovery-related publications of the authors. Following this sensitivity check, the initial search was adapted in stage 2 by

including additional terms for mental health ('psychol$ health' OR 'psychol$ illness$' OR 'psychol$ disorder' OR psychol$ problem' OR 'psychiatr$ health', OR psychiatr$ illness$' OR 'psychiatr$ disorder' OR 'psychiatr$ problem') and for the conceptualisation of recovery ('theme$' OR 'stages' OR 'processes'). The final search strategy used for the review is presented in Table 3.2.

Table 3.2: Final search strategy

Search Terms	
1) 'mental health' OR 'mental illness$' OR 'mental disorder' OR mental disease' OR 'mental problem' OR 'psychol$ health' OR 'psychol$ illness$' OR 'psychol$ disorder' OR psychol$ problem' OR 'psychiatr$ health', OR psychiatr$ illness$' OR 'psychiatr$ disorder' OR 'psychiatr$ problem' hw.kw.ti.ab	Population of interest
2) 'recover$. hw.kw.ti.ab	Truncated recovery term covering recovery, recover, recovering etc.
3) 'theor$', OR 'framework', OR 'model', OR 'dimension', OR 'paradigm' OR 'concept$' OR 'theme$' OR 'stages' OR 'processes' hw.kw.ti.ab	Conceptualisations of interest
4) 1. AND 2. AND 3.	Include if reference contained the terms in searches 1, 2 and 3.

The search was limited to English language papers. Duplicate articles were removed within Reference Manager Version 11.

3.2.2 Eligibility criteria

Papers that explicitly described or developed a conceptualisation of personal recovery from mental illness were eligible for inclusion in the review. A conceptualisation was defined as a visual or narrative model, a framework, or themes and factors of recovery. To be included papers were required to meet the following criteria:

1. Present a conceptualisation of personal recovery that could be succinctly extracted
2. Describe an original model or framework
3. Based on either a synthesis of available literature or primary research involving quantitative or qualitative data from at least three participants and
4. Available in printed or downloadable format.

Additionally, the following exclusion criteria applied:

1. Non-English language
2. Opinion article not based on a review of the literature

3. Individual case studies
4. Volumes or whole books on recovery that did not present a succinct and useable summary
5. Focusing on a clinical model of recovery, including defining remission criteria or recovery from substance misuse, addiction or eating disorders. Papers where the primary population was individuals with substance misuse, addiction or eating disorders were excluded.
6. Presents regression analyses of the participant characteristics associated with clinical recovery and
7. Dissertations and doctorate theses (due to the availability of the articles).

3.2.3 Data Abstraction and Quality Assessment

An inclusion status table was created to record decisions regarding the eligibility of retrieved papers. All papers were rated by the thesis author, and the inclusion status of a random sub-sample of 80 papers was also rated by two further members of the REFOCUS team. Disagreements were resolved by discussion. Acceptable concordance was pre-defined as agreement on inclusion status for at least 90% of papers. All included papers were tabulated and quality assessed by the thesis author. For qualitative papers, the RATS qualitative review checklist [140] was applied with the Effective Public Health Practice Project quality tool [141] used for quantitative research. The RATS checklist assesses the quality of qualitative research based on four components which spell out the acronym RATS; Relevance of the study question, Appropriateness of qualitative methods, Transparency of procedures and Soundness of interpretive approach. Quality assessment was not used to exclude papers due to the debates within the literature regarding the appropriateness of quality assessment tools for qualitative research [142]. Instead, the primary papers rated as high quality were used to develop the initial conceptual framework with a random selection of medium and low quality papers used to validate the findings. To quantify the quality of the qualitative papers, the questions included in the RATS checklist were dichotomised i.e. yes (1 point) or no (0 point), giving a possible total of 25. High quality was defined as a score of 15 or more on the RATS, with medium quality papers scoring 14 and low quality papers 13 or less.

3.2.4 Data Analysis - narrative synthesis process

A narrative synthesis approach following the guidelines developed by Popay and colleagues was applied [143]. Narrative synthesis was adopted due to the flexibility with which quantitative and qualitative research studies can be combined within this analysis method.

This matched not only the overall mixed methods design of the thesis, but also the subtle realism epistemology adopted (see section 1.4.3). The Popay narrative synthesis guidelines outline four stages of a narrative synthesis: identifying and developing a theory; developing a preliminary synthesis; exploring relationships within and between studies; and assessing the robustness of the synthesis. As the review focused on developing a Conceptual Framework rather than assessing the effectiveness or implementation of an intervention, the initial stage of identifying relevant theory was not applicable. Table 3.3 highlights the tools proposed by Popay and colleagues which were used and not used in the present review [143].

Table 3.3: Narrative synthesis tools used in the review

Tools used in the present review	Tools not applicable for the present review
Tabulation	Textual descriptions
Translating data: thematic analysis	Grouping and clusters
Vote counting	Transforming data into a common rubric
Tabulation of different sub-groups	Translating data: content analysis
Reflecting critically on the process.	Visual representation of the relationship
Use of expert panel as a consultative resource.	between studies e.g. graphics, plots etc.
	Idea webbing and conceptual mapping
	Methodological and theoretical triangulation
	Qualitative case descriptions
	Conceptual triangulation
	Weight of evidence
	Best evidence synthesis
	Use of validity assessment

Tools used within the review were chosen based on their suitability. For example, transforming the data into a common rubric such as an effect size was not possible as the majority of data included in the review were qualitative. Many of the tools overlap in their outcomes. For example, both tabulation and textual descriptions produce summaries of the main findings. Given the number of studies included in the review, tabulated data were deemed easier to read and follow, and allowed for comparisons across the different studies based on key features such as country, study, method and population. The narrative synthesis was augmented with the addition of expert consultation panels. The aim of this methodological extension was to increase the quality of the Conceptual Framework by ensuring that different stakeholder perspectives such as service users, staff and researchers were taken into account. The narrative synthesis process is shown in Figure 3.1. The dotted line within the diagram highlights the interaction between the different stages, whereby latter stages have an influence on the development of the synthesis. For example, exploring the relationships between papers in Stage 2, modifies and influences the preliminary synthesis developed in Stage 1.

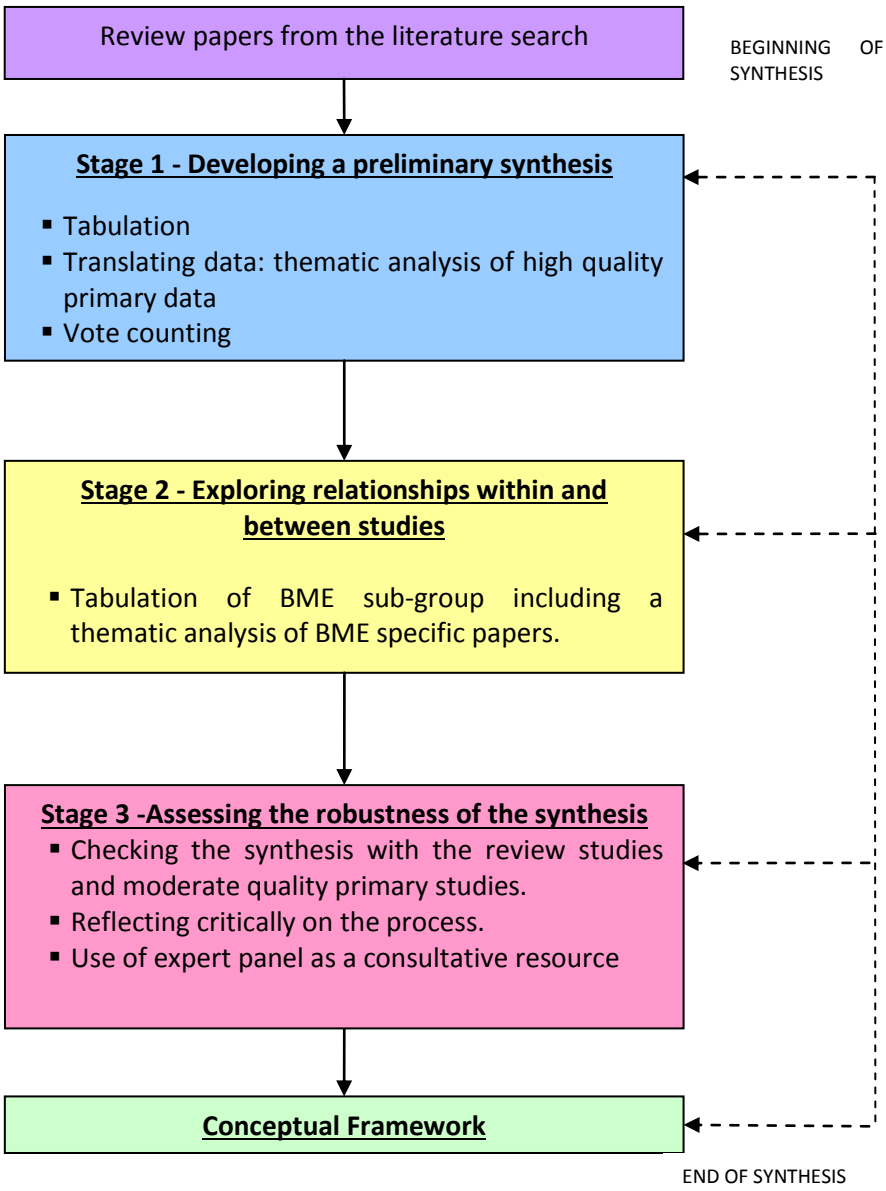


Figure 3.1: Narrative synthesis process

Stage 1: Preliminary synthesis

For each of the included papers the following data were extracted: methodology, target population, study location and main findings of the paper including the key terms and components of the recovery conceptualisation described. Due to the high number of qualitative studies, the preliminary stages of the narrative synthesis focused upon the high quality primary qualitative papers (RATS ≥15). Thematic analysis of the high quality primary studies was used to identify the themes occurring within the data. To identify the main themes and sub-themes, relevant extracts from each text were collated and grouped. An inductive open coding approach was undertaken using NVivo QSR qualitative analysis software, Version 8. Themes were constantly checked against the original data to ensure fidelity to the inductive and data-driven approach. To ensure that the themes remained

consistent, coherent and distinctive, each new theme emerging from the data was checked against those already coded using constant comparison [144].

All themes were coded at the semantic level, with little attempt to infer beyond the surface or explicit meaning of the text. This approach was appropriate given the secondary nature of the synthesis undertaken.

The thesis author led the coding with the four coders meeting as a team to collectively review the initial list of themes and group the categories into an organising framework. The categories within the framework were data-driven and used the language of the original data extracts to inform their headings and definitions [144]. Each category included in the framework was defined, to improve consistency of coding.

Once all the themes had been extracted from the high quality papers, vote counting was carried out using all of the included papers. The aim of vote counting was to quantify the number of papers in which the initial themes occurred. This meant that for each paper, a category, if present, was only counted once, regardless of the number of times it appeared in the text. This process helped with decisions about the ordering of categories within the framework. For example, if a theme appeared in the majority of papers, it was included as a higher level category, whereas themes included in only one or two papers were included as lower level categories. The definition of each theme was checked against the data during the vote counting process to ensure that each category accurately represented the data. The vote counting process also identified areas omitted from the initial thematic analysis.

To improve reliability, at least two members of the REFOCUS team (always including the thesis author) double-rated 25% of papers during the vote counting. Disagreements between raters were resolved by discussion. From the thematic analysis and vote counting process, a preliminary Conceptual Framework was developed.

Stage 2: Exploring relationships within and between studies: BME sub-group analysis

A pre-planned sub-group thematic analysis was undertaken focusing on black individuals within the UK. The aim was to assess the extent to which the preliminary framework developed in Stage 1 matched the perceptions of black individuals. However, due to the paucity of papers relating specifically to black individuals within the UK, the inclusion criteria

was extended to include papers addressing conceptualisations of recovery from other minority ethnic populations.

The same coding process was used as in Stage 1 with themes and sub-themes identified using an inductive and data-driven open coding approach. A particular emphasis was placed on emerging themes which were absent from the preliminary framework developed in Stage 1. The themes and definitions from Stage 1 were subsequently adapted to fully incorporate the new data emerging from the sub-group analysis. Areas of difference between Stage 1 and 2 were recorded as new themes within NVivo.

Stage 3: Assessing the robustness of the synthesis

To test the robustness of the emerging Conceptual Framework from Stages 1 and 2, a sample of review papers and moderate quality primary studies were thematically analysed until category saturation was achieved. The thematic analysis used the same process described in Stages 1 and 2, with a particular emphasis placed on identifying themes not already included in the analysis. The resulting themes were then compared with the preliminary framework.

To investigate the content validity of the Conceptual Framework of Personal Recovery, including themes developed for BME communities, a consultation involving the REFOCUS expert panels, including the BME virtual consultation panel was conducted. Consultation questions for the advisory panels included the following:

1. Should any of the lower order categories be promoted to a higher level or be merged together?
2. Have we missed any important areas of recovery? If so, what are they?

The consultation panel were also asked for any other comments.

3.3 Results

The search process and total number of articles included in the review are shown in Figure 3.2.

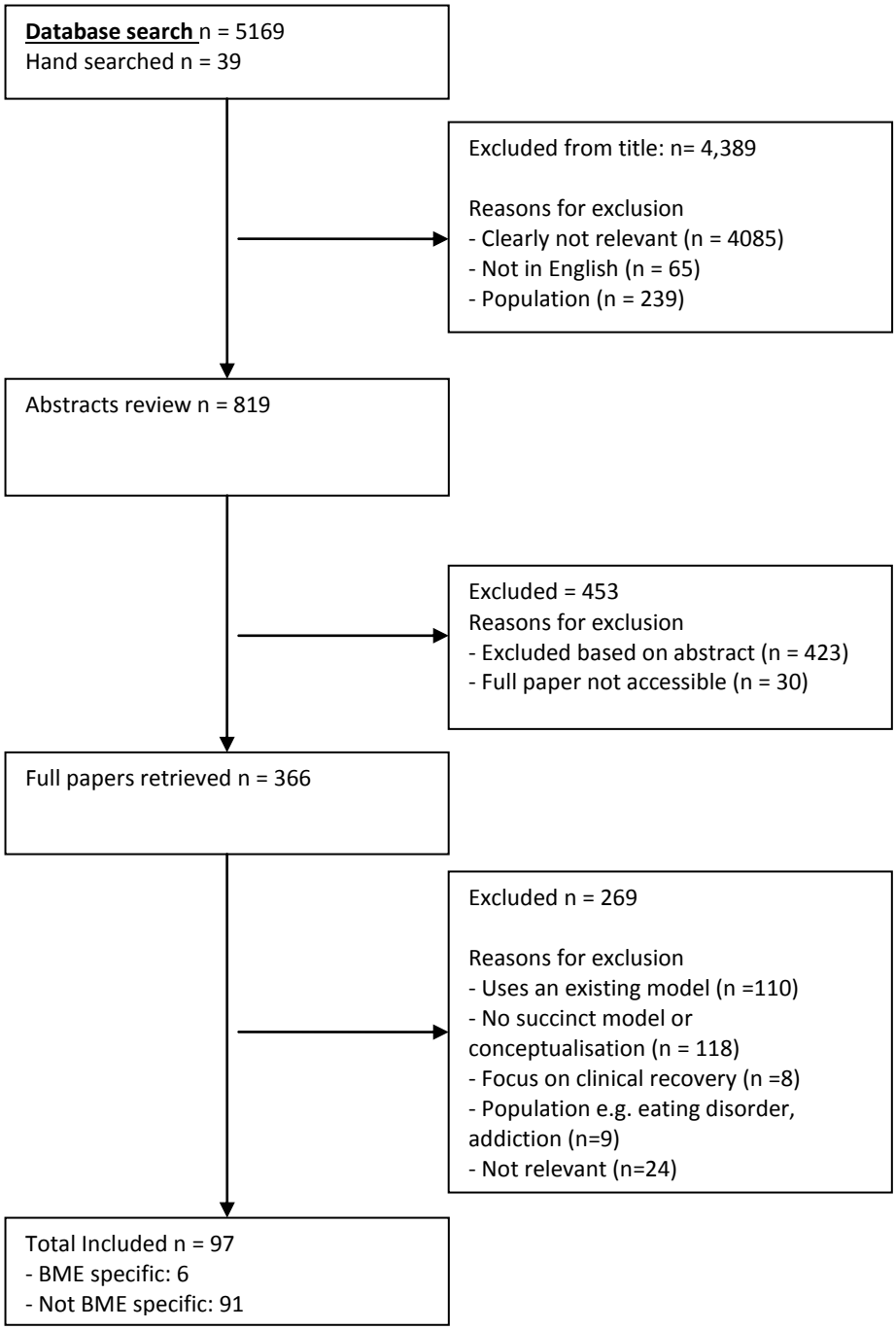


Figure 3.2: Flow diagram of the search process

Three hundred and sixty-six full-text papers were assessed for inclusion, of which 97 met the eligibility criteria. Of the 97 papers included in the review, 87 were original conceptualisations of personal recovery and 10 were secondary papers reporting further details and data extracts relating to one of the 87 original conceptualisations identified. The 87 primary papers comprised 35 qualitative studies (e.g. focus groups, interviews, and ethnographic studies), two quantitative studies utilising survey designs, 25 literature reviews, 7 book chapters, six

consensus statements or policy documents and 12 documents that did not fit into any of the above categories as they included multiple study designs. The included studies table is shown as part of the published paper in Appendix 2, and the eligibility table for all full-text papers assessed during the review is shown in Appendix 3.

Stage 1: Thematic analysis

The RATS checklist for qualitative research was applied to 33 of the 35 qualitative papers. Quality assessment was not possible for two of the qualitative papers as both papers contained a synthesis of multiple study designs. An average score of 15.2 was obtained, with 16 of the 33 qualitative papers meeting the criteria for high quality (defined as a score of 15 or more on the RATS). These 16 papers were used for the thematic analysis.

The thematic analysis led to a preliminary framework which was organised into three superordinate categories, namely Recovery Principles, Recovery Processes and Recovery Stages. This thesis focuses on the Recovery Processes due to their proximal relevance to both clinical practice and research. For more information on the Recovery Processes and Recovery Stages see the published paper in Appendix 2. The codes included in Recovery Processes were organised into seven high-order categories (Connectedness, Hope and Optimism, Identity, Meaning in Life, Empowerment, Rebuilding Life and Social Inclusion).

Stage 1: Vote counting

Following the initial thematic analysis, all papers regardless of their quality rating and methodological design were included in the vote counting process. The vote-counting process did not change the three superordinate categories of the preliminary framework. Two of the seven higher-level Recovery Processes categories (Social Inclusion and Rebuilding of Life) were removed from the framework. Connectedness as a category included many data extracts and themes also included in the Social Inclusion category. As a result, Social Inclusion was removed and subsumed within the second and third order Connectedness categories of "support from others" and "social support". Rebuilding of Life was removed as a higher order category and included within Meaning in Life as many of the data extracts were included in both categories. This coupled with the low frequency of Rebuilding of Life in the vote counting process, suggested that the code was not a higher order category. Additionally, nine new codes were created, 18 existing codes modified and two codes removed as they were only included in one paper. The Recovery Processes resulting from the stage 1 preliminary synthesis (thematic analysis and vote counting) are described in detail below.

Stage 1: Recovery Processes

The Recovery Processes themes concentrated on aspects of recovery, including specific outcomes or areas that the individual focuses on, and on areas required for the person to recover. Within the superordinate category of Recovery Processes, 69 themes were identified and organised into five categories (Connectedness, Hope and Optimism for the Future, Identity, Meaning and Purpose in Life and Empowerment, given the acronym CHIME). Within each higher order category, a number of sub-categories emerged. These are shown in Table 3.4.

Table 3.4: Recovery Processes

Recovery Processes	
1st and 2nd Order	**3rd Order**
1. Connectedness	
1.1. Peer support and support groups	
	1.1.1. Becoming a peer support worker or advocate
1.2. Relationships	
	1.2.1. Establishing new relationships
	1.2.2. Building on existing relationships
	1.2.3. Intimate relationships
1.3. Support from others	
	1.3.1. Social support
	1.3.2. Active or practical support
	1.3.3. Support from professionals
2. Hope and optimism about the future	
2.1.Hope inspiring relationships	
	2.1.1 Role models
2.2. Motivation to change	
2.3. Belief in possibility of recovery	
2.4. Positive thinking	
2.5. Having dreams and aspirations	
3. Identity	
3.1. Dimensions of identity	
	3.1.1. Cultural identity
	3.1.2. Sexual identity
	3.1.3. Ethnic identity
3.2. Rebuilding/ redefining a positive sense of self	
	3.2.1. Self-esteem
	3.2.2. Acceptance
	3.2.3.Self-confidence and self-belief
3.3. Overcoming stigma	
	3.3.1. Self-stigma
	3.3.2. stigma at a societal level

Recovery Processes	
1st and 2nd Order	**3rd Order**
4. Meaning and purpose	
4.1. Meaning of mental illness experiences	
	4.1.1. Accepting or normalizing the illness
4.2. Spirituality (including development of spirituality)	
4.3. Quality of life	
	4.3.1. Wellbeing 4.3.2. Meaningful structured activities 4.3.3. Meeting basic needs
4.4. Meaningful life and social goals	
	4.4.1. Active pursuit of previous or new life and social goals 4.4.2. Identification of previous or new meaningful life and social goals
4.5. Meaningful life and social roles	
	4.5.1. Active pursuit of previous or new life and social roles 4.5.2. Identification of previous or new meaningful life and social roles
4.6. Rebuilding of life	
	4.6.1. Resuming with daily activities and a daily routine 4.6.2. Developing new skills
5. Empowerment	
5.1. Personal responsibility	
	5.1.1.self-management 5.1.2.Positive risk-taking
5.2. Control over life	
	5.2.1.choice 5.2.2 knowledge and information 5.2.3. Regaining independence and autonomy 5.2.4. Self-determination 5.2.5. involvement in decision-making
5.3. Focusing on strengths	

The five categories of Recovery Process are now considered in detail.

Connectedness

Connectedness not only related to the individual's relationship with others but went beyond this to talk about connections with society and feeling connected to others.

> *"Having supportive others, whether they are family members, professionals, community members, peers, or animals, to provide encouragement through the*

difficult times and to help celebrate the good has been noted as being critical to recovery" [[145] p43]

Three components of Connectedness were identified: Peer support, Support from others, and Relationships.

In many studies, the importance of peer support or support groups was explicitly mentioned, with the availability of support groups and opportunities to give support to others, either informally or as peer support workers key facets. Increased self-esteem and exchanging coping strategies were some of the outcomes achieved from peer support.

> *"Peers can spark and support recovery through formal self-help, informal encounters, mutual assistance and exposure to their stories of recovery. Invaluable practical information, insight and support are available through peer groups"* [[137] p340]

In addition to the support of peers, individuals mentioned support from a range of other people as being important in their recovery. This sub-category, "support from others", included not only social support but also specific reference to both active and practical support. For some individuals the practical support they received from friends and family was invaluable. In many cases, individuals described how having someone to take charge of daily activities enabled them to concentrate on their own mental wellbeing.

> *"Practical support while in hospital was appreciated, too. Cathy's family flew to Australia, stayed at the hospital while she was there and brought her back home to the coast where she spent "healing time""* [[146] p80]

Although for many, recovery could occur without professional intervention, this did not negate the role that mental health professionals could play in an individual's journey. In particular, supportive professionals that attended to the needs of the individual were seen as having a positive impact.

> *"Mental health professionals play a significant role in fostering recovery. According to participants, the nature and quality of professional treatment profoundly influenced their ability to recover. Trusting and egalitarian relationships with professionals can provide the support necessary to move forward in recovery."* [[147] p54]

<u>*Hope and Optimism for the future*</u>

Hope was defined by a number of secondary categories, namely "having the motivation to change", "having dreams and aspirations", "a belief in the possibility of recovery" and

"positive thinking". All of these categories emphasise how recovery is an active process and one which requires self-determination. Recovery is not something that is simply "done" to the person.

> *"Recovery involves our hopes for a better future, which involves a process of change and desire for change."* [[148] p58]

Central to many factors defining hope was the presence of hope-inspiring relationships. These relationships could be with family, friends, professionals or with a higher power and were characterised by a belief in recovery. This included the individual having belief in their recovery as well as others believing in the individual.

> *"Participants indicated that recovery is above all else a social process, with supportive relationships helping to foster hope by communicating the expectation that participants could live productive and satisfying lives"* [[147] p52]

For some individuals, role models provided hope for the future, with peers acting as role models for many people. Hearing about the success of others and learning from other people's recovery stories were both hope inspiring and often provided the motivation to change.

> *"… role modelling provided by peers, and professionals who create "environments of hope" by believing in the individual's ability to get better and providing opportunities to act."* [[138] p253]

Identity

According to Anthony, recovery involves more than just overcoming the mental illness [8]. Part of the process of overcoming the effects of mental illness relates to a person's identity. Within this category, redefining and rebuilding a positive sense of self were seen as key processes.

> *"Mental distress frequently involves the loss of the sense of the self, often coupled with what can be a disempowering experience of mental health services. This research suggests that the rebuilding of the self is a key element to the recovery process."* [[148] p57]

An important part of an individual's sense of self was acceptance, which included accepting one's self and being accepted by others. For a lot of individuals, however, building a positive

identity went beyond this, and for some included incorporating their experiences into a positive sense of self.

> *"Respondents' efforts to reintegrate who they are with their illness required acceptance and the establishment of understanding and perspective in relationship to the past."* [[149] p38]

For many the illness was seen as just one part of a multi-dimensional person. This was linked to the idea that an individual's identity could not be viewed in a unitary way. Instead multiple dimensions of identity were important and included their cultural, ethnic and sexual identity. In particular, having mental health professionals and services which valued the different dimensions of identity were crucial.

> *"Actually listening to me as an individual and stop assuming things, yeah, I suppose that would have probably helped a lot."* [[150] p53]

A second, but related area to overcoming the effects of the mental illness was overcoming stigma. This related to self-stigma as well as stigma at a societal level, which may involve mental health professionals actively working with the community to reduce stigma.

> *"Another important passage on the journey of recovery involves working to reduce the sense of internalized stigma and addressing external stigma."* [[137] p340]

Meaning and Purpose

Meaning and purpose in life was a broad category and included many interrelated elements as secondary and tertiary themes. In general individuals described the development of meaning and purpose as a key process in the recovery journey:

> *"Recovery is about finding a framework that explains their experience"* [[138] p253]

More specifically, meaning and purpose was divided into the following subcategories: spirituality, meaning of mental illness experiences, rebuilding life, quality of life, developing meaningful life and social roles, and developing meaningful life and social goals.

As already touched upon in the identity section, recovery for some individuals included understanding or finding meaning in their mental illness experience. Giving an experience meaning and purpose was seen as normalising that experience, which in itself could have positive implications.

"De-emphasizing the illness offers a strategy in the management of stigma. Through normalizing and relativizing the illness, individuals may take an active stance against stigma." [[151] p402]

Connecting with a higher power and developing spirituality often aided the individual to develop an understanding of their experience and provided a source of support and encouragement. Rather than focusing on organised religion or a specific faith, many of the participants chose to talk about spirituality in abstract terms.

"The greatest help comes when individuals are able to connect to some source of enlightenment: a community of practising Buddhist, the bible, treatises of philosophy or physics" [[138] p253]

Meaning and purpose could also be attained through more concrete areas of an individual's life including through meaningful activities. These activities could include employment, recreation and education and were often linked to the social roles of individuals.

"Having a job was also a part of being normal. This was not necessarily an 8:00 a.m. to 4:00 p.m. job, but a work situation that was experienced as valuable and meaningful, and in a regular setting as opposed to sheltered occupation" [[152] p133]

Having meaningful life and social goals frequently related to goal setting and having goals in areas outside of mental health services. For many participants, recovery involved rebuilding their lives by taking on new meaningful life roles and developing new skills. This included pursuing new goals.

"Further down the path, recovery-enhancing change often meant picking up new challenges and responsibilities. Two types of change were most frequently mentioned: change of residence, and becoming involved in more demanding daily activities (specifically, getting a job or taking up further education)." [[146] p59]

Related to many of the above themes was the broad category of quality of life. This was seen as both a process and an outcome. Important to a lot of individuals was ensuring that their basic needs were met. This included the provision of adequate housing and financial support which contributed to an individual's general wellbeing as well as their overall quality of life.

"Recovery crucially depends on issues such as secure accommodation, financial freedom and certainty, and basic human rights and being a citizen." [[153] p3]

Empowerment

Many of the sub-categories within empowerment described the ways in which an individual achieved empowerment. Empowerment was made up of three distinct areas: "having control over life", "personal responsibility" and "focusing on strengths". Although many of the themes related to mental health services, empowerment was broader than this and included becoming an empowered citizen.

> *"The research suggests that empowerment is central to the recovery process and people who experience psychosis employ a variety of strategies to empower themselves."* [[148] p58]

An important part of control over life was having control over the mental illness including treatment. To achieve this control, knowledge and information were important. Individuals wanted information about the causes of illness as well as the treatments and services available. Having information was particularly important in enabling individuals to make informed decisions about their care. In particular, being involved in decisions and being treated as an equal by mental health professionals were commonly mentioned.

> *"Participants responded positively to collaborative and personalized relationships with mental health professionals and others who put them in charge of directing what they needed, respected their requests or asked directly what they could do to be of assistance."* [[154] p617]

Related to the individual's ability to have control over their life was the notion of personal responsibility. Not only was it important for individuals to take responsibility for their own recovery, mental health professionals needed to allow the individual to take responsibility.

> *"Participants described the importance of themselves taking an active role to engage in recovery. This can be frightening, and it is important to have personal incentives and adequate support in the process."* [[153] p4]

One way that individuals could take personal responsibility for their own recovery was through self management which included attending to both physical and mental health. This included the use of coping strategies, self help materials and seeking professional intervention:

> *"Multiple coping strategies had been adopted by different recovered group members. The fully recovered protagonists were able to detect the warning signs of their*

symptoms and return to professional help, and further to appeal to self potentials and strengths and engage mutual help with their personal social network." [[155] p355]

Personal responsibility could include positive risk taking, particularly in the context of care planning and goal setting. Mental health professionals needed to allow individuals to take positive risks. This enabled individuals to take control over their lives and promoted feelings of personal responsibility.

> *"When participants took risks and engaged in activities others thought they were incapable of and succeeded, they were able to test their own resistant assumptions about their ability to live productive and satisfying lives. This allowed them to develop confidence and a sense of self-worth."* [[147] p53]

The final area covered in empowerment was focusing on strengths. Individuals often talked about adopting roles building upon their personal strengths. Within this context, strengths including utilising both personal resources and that of the community:

> *"A changing focus from symptoms to strengths and health and wellness, is seen as a foundation of recovery. The person in recovery and those who care about them focus on how the individual can use the internal and external resources available to build a better life."* [[156] p4]

Stage 2: Exploring the relationships between studies

Six of the 97 papers included in the review were based on data from non-majority participants. Details of the six papers are shown in Table 3.5.

Table 3.5: BME sub-group analysis (n=6)

Study Reference	Country	Method	Participants / inclusion criteria	Main findings	Quality rating
NHSSCOTLAND2008[157]	Scotland	Three exploratory community development projects that collated the recovery experiences of approximately 50 BME individuals.	The three projects comprised of Saheliya (a group of women from different BME communities), the NHS Lothian Minority ethnic mental health project and a project conducted by Men in Mind.	Themes included the meaning of recovery and also factors that help keep people well. Recovery means: -using positive happy people for support -knowing what will keep me well -knowing when to say no -having regular contact with people -having information available to explain things to my family -not focusing just on illness Within the report, cultural differences were often seen as adding to the pressures experienced by people with mental health problems. Participants felt the need to hide their mental health problems from other members of the community.	Not a formal research project
ARMOUR2009 [154]	USA	Secondary data analysis of the qualitative data collected from an African-American subset of a larger study [149]. Semi-structured interviews employing a hermeneutic phenomenological approach were conducted at three time points with nine African-American	Inclusion criteria: -diagnosis of schizophrenia, schizoaffective, bipolar, chronic major depression, and substance abuse -involvement in the agency for 4 months or less	Four themes were identified of which the final two were only common in the experiences of the African-American sub-group -striving for normalcy -striving to stay 'up' -coping with the consequences of illness -lean on supports that watch over and out for me. Interdependency, spirituality and discrimination, including racism were all reflected in the experience of African Americans.	RATS 11/25

Study Reference	Country	Method	Participants / inclusion criteria	Main findings	Quality rating
		with serious and persistent mental illness. The paper focused on a culturally sensitive approach to the research, particularly concerning data analysis.	-no evidence of a primary substance dependence diagnosis or organic brain syndrome.		
NICHOLLS 2007 [156]	UK	The review synthesised key findings in user-led research. Two focus groups conducted with BME individuals assessed the essentials of recovery.	No information provided about the participants.	The essential ingredients common to recovery were: 1. Hope. 2. Feeding the flowers - strengths. 3. Belief in the person. 4. Meaning. 5. Coming to terms with the past. 6. Positive identity – in the context of holding an undervalued position in society which may be related to negative stereotypes. 7. Social inclusion – the research highlighted the "cultural dissonance" which made social inclusion particularly hard for black individuals. 8. Empowerment and responsibility / independence and self-control. 9. Mental Health System. 10. Culture and the cultural context. 11. Carers.	Not systematic. Qualitative research not described
MENTAL HEALTH PROVIDERS FORUM 2009 [30]	UK	Pilot study to test whether the recovery star was applicable to BAME	BAME individuals using mental health service	10 dimensions of the recovery star included: 1) Managing mental health 2) Self care	Not primary research. Not rated.

Study Reference	Country	Method	Participants / inclusion criteria	Main findings	Quality rating
		population		3) Living skills 4) Social networks 5) Work 6) Relationships 7) Addictive behaviours 8) Responsibilities 9) Identity and self esteem 10) Trust and hope Issues were raised regarding the following areas of the recovery star and its use within BME communities: - Cultural appropriateness of the language - Religion and spirituality - Cultural understandings of mental health - Predominance of individualistic notions of recovery.	
SOUTHSIDE PARTNERSHIP FANON 2008 [150]	UK	Semi-structured interviews and questionnaires. The research was conducted by community researchers who were individuals from black backgrounds with experience of using mental health services.	African and African Caribbean male service users recruited using purposive and snowballing sampling methods. A number of local voluntary organisations were approached to assist with the recruitment.	The research identified a number of barriers to recovery, these included stigma and discrimination. 43 factors were identified as important to recovery. This included self-identity and hope. Additionally, areas not as predominant in the mainstream literature were identified as important for black individuals. These included the importance of spirituality and religion, cultural appropriateness of services, overcoming racial stigma and discrimination, being involved in a community and learning about cultural heritage.	RATS 20/25

Study Reference	Country	Method	Participants / inclusion criteria	Main findings	Quality rating
			In total 21 interviews and 30 questionnaires were analysed.		
LAPSLEY 2002 [146]	New Zealand	Semi-structured interviews with individuals with lived experience. Narratives were developed from the interviews	40 new Zealanders (Maori and non-Maori women and men) who once had a disabling mental health problem.	The paper presents a bi-cultural view of mental health recovery based upon the perspectives and experiences of Maori and non-Maori people. One section of the report specifically focuses on the role of culture in recovery. Two models of recovery were developed. These were RECOVER and HEART: RECOVER which focused on strategies for recovery: Reading, Emotional growth, Change of circumstances, Others (experiencing social support) Virtues (practising them) Etceteras (additional Recovery strategies); Repeating strategies that work HEART = processes of change Hope, Esteem, Agency, Relationship and connection, Transitions in identity.	RATS 20/25

An additional six papers describing BME projects were included for the purposes of the sub-group analysis. Five of these papers described Scottish projects [158,159,160,161,162] and the sixth paper described research by the Social Perspectives Network, including a number of focus groups with BME participants [163]. These six papers were identified in Stage 1 but excluded as they did not present an original conceptualisation of recovery. They were included in the sub-group analysis as they included additional quotations and information about the projects (Scottish projects) and important contextual information (Social Perspectives Network study). This resulted in 12 papers included in the analysis.

There were many similarities between papers focusing on non-majority and majority populations. Many areas of the preliminary Conceptual Framework were highlighted as important for people from BME backgrounds. In particular hope in the possibility of recovery, having their basic needs met, being able to access information about treatments and the support of others were all crucial to recovery. The below quotations are typical of the themes occurring within the data.

> *"Hope is of central significance. If recovery is about one thing it is about the recovery of hope, without which it may not be possible to recover and that hope can arise from many sources."* [[156] p4]

> *"The support of others, crucial at the beginnings of recovery, remained of key importance right through the process. After their directions had become clear, people developed a better ability to make use of support and to recognise what kinds of support were actually helpfu.l*" [[146] p64]

Despite these general similarities, five areas of difference emerged from the sub-group analysis. These are now considered in detail.

Difference 1: Spirituality and religion

Although spirituality was important for many individuals regardless of their ethnicity, this theme was particularly important to individuals from BME backgrounds.

> *"The knowledge that there is a higher power within the universe and having a strong sense of faith were sources of comfort and support for many during periods of crisis. These respondents also believed that their faith in God helps them to survive and will continue to sustain them on their journey to recovery."* [[150] p51]

Being part of a faith community and having a religious affiliation was seen as a major force behind an individual's recovery.

> *"Participants raised the importance of religion and the membership of a faith group in the lives of many BAME ethnic groups, the role it plays in people's sense of wellbeing and cultural identity and its significance on their journey of recovery."* [[30] p17]

For people from minority ethnic backgrounds, spirituality was more often described in terms of religion and a belief in God as a higher power, contrasting with the majority population papers where spirituality was often conceptualised in abstract terms.

> *"Among these distinctive themes, the intimate relationship with religiosity and spirituality was perhaps the most pronounced. One striking finding was the degree to which the participants' relationship with religion, and in particular, with organized religion was described as a relatively non-conflicted one."* [[154] p616]

Difference 2: Stigma and discrimination

Although overcoming stigma was a universal theme, it was particularly important for people from minority ethnic communities. The types of stigma differed, with BME participants describing the stigma associated with race, culture and ethnicity, in addition to the mental health stigma.

> *"Is it a problem with my skin color or because I have mental health issues. Which is it?"* [[154] p612]

Furthermore, being an individual from a minority ethnic group seemed to accentuate the stigma of mental illness, as the person often viewed themselves as belonging to multiple stigmatised and disadvantaged groups.

> *"For people who have an existing aspect of identity that is undervalued in mainstream society such as people from Black and minority ethnic including Irish communities; lesbians, gay men, transsexuals and bisexuals; people with learning and physical disabilities, these struggles may be intensified."* [[156] p5]

This difference was also captured in the way in which individuals from ethnic minorities saw themselves as recovering from racial discrimination, stigma and violence, and not just from a period of mental illness.

> *"I have realised that I am recovering from the discrimination as much as I am recovering from the mental health problems."* [[159] p11]

Difference 3: Culturally specific facilitating factors

The cultural sensitivity and appropriateness of mental health services was consistently mentioned across all studies as a culturally specific facilitating factor and represented a new category in the analysis. Many participants highlighted the positive impact that a culturally sensitive service has on their subjective experience.

> *"The need for staff training in cultural competency, working with service user's sense of shame, denial and in creating a space in which service users feel safe to share feelings and/or disclose personal experiences was also highlighted, to help staff explore culturally specific content with appropriate sensitivity."* [[30] p5]

Mental health professionals with a shared cultural or ethnic identity were also favourably discussed.

> *"Half the Maori participants discussed encountering Maori health service providers, and this generally had a positive impact on them. They enjoyed being with other Maori staff and patients, usually found the treatments they received appropriate, and appreciated learning from staff."* [[146] p84]

Culturally specific facilitating factors included the use of traditional therapies and faith healers as well as belonging to a particular cultural group or community.

> *"Several of the SPN focus group participants talked about the importance of spending time with others with shared beliefs and values; and of exchanging ideas and experiences with other Black and minority ethnic people."* [[156] p4]

Difference 4: Mental health system-level barriers

In addition to stigma and discrimination as barriers to an individual's recovery, barriers also existed at the level of the mental health system. Participants within the studies often commented on the lack of cultural understanding within mental health services.

> *"Now what you find with the psychiatrists, especially white psychiatrists, they don't understand ethnic minority backgrounds, so when they are talking about certain things, they take it in perception of 'that's peculiar' because they don't understand, it's not I'm peculiar, it's just that people live differently, different ways of living…"* [[150] p51]

For many this system-level barrier was overcome through the utilisation of culturally sensitive services and other culturally specific facilitating factors discussed above.

Difference 5: Individualist vs. collectivist values

There was also a difference in the values present within the BME sub-group. The notion of self-reliance and the prominence given to the individual regaining a sense of independence were promoted as a goal of recovery in many of the majority population papers. Although these were important for many people from minority ethnic backgrounds, this privileges an individualist notion of recovery. For many ethnic minority communities, a collectivist viewpoint was prioritised with recovery described in terms of social roles and relationships within the community.

> *"In some cultures the highest level of attainment for recovery may be defined in terms of social relationships rather than individual autonomy."* [[30] p5]

The collectivist viewpoint often included placing the needs of the family above the needs of the individual and further stressed the importance of social roles.

> *"Participants did not view themselves as independent of separate from their families. Rather the concept that "we're in this together" was central and meant both that family was a source of support and mutual obligation and also a group to which they were accountable."* [[154] p614]

Throughout the papers, collectivist values were seen as both facilitating and hindering factors. Whilst many individuals discussed the hope and support they received from their collectivist identity, for others the community added to the pressures of mental illness.

> *"People often felt under pressure to hide their experience of ill health from their families and others in their community, or to cope on their own. Sometimes, this was linked to a community not recognising or understanding concepts around mental health and wellbeing.. Some people talked about the pressures on people in their community to fulfil many roles which sometimes became too difficult to manage."* [[161] p10]

Furthermore, the negative impact of discrimination and stigma was felt not only at the level of the individual, but also at the collectivist level, with the whole family being adversely affected.

> *"My family needs help to keep them going. My mum would appreciate some support as our community's attitude is very negative towards mentally ill people."* [[157] p11]

Stage 2 - modifications to preliminary Conceptual Framework

To incorporate the differences from the sub-group analysis, the existing categories from the Stage 1 preliminary framework were modified in the following five ways:

1. The definition of Connectedness was expanded to include reference to collectivist values.

2. The importance of cultural and community groups as culturally specific facilitating factors was captured with the addition of "being part of a community" within connectedness. This theme refers to being part of the wider community and could include membership in different communities, e.g. religious, local community, service-related etc.

3. The definition of spirituality made reference to religion as a primary source of support as well as to abstract notions of spirituality.

4. "Information for family and communities" was added as a sub-category of "Knowledge and information". This category highlights the need for information and knowledge to be provided to a wider range of people, including the person's family, friends and community.

5. "Culturally sensitive services" was added as a subordinate category within care planning and accessing services. This includes having access to culturally sensitive as well as culturally specific services if wanted by the person.

Stage 3: Validation

To improve the reliability and validity of the Conceptual Framework, a process of critical appraisal including three components was undertaken:

Firstly, during the systematic search conducted in Stage 1, to ensure the internal consistency of the review, a proportion of papers were double rated for inclusion. The resulting level of concordance achieved between raters was 91%.

Secondly, to validate the preliminary Conceptual Framework, a selection of five moderate quality primary papers and three high quality review papers were thematically analysed.

Category saturation was achieved ensuring that the Conceptual Framework and resulting BME sub-group analysis did not omit any areas essential in the conceptualisation of recovery. Although no new themes or subthemes were identified in the validation process, a number of definitions were refined to more accurately represent the data. Two modifications to the Conceptual Framework were made. “Maintaining good physical health” was changed to “Maintaining good physical health and healthy, balanced lifestyle ” and “Positive thinking” was changed to “Positive thinking and valuing success”.

Finally, a consultation was conducted with the REFOCUS expert panels including the BME virtual consultation panel. In total, 23 (43%) individuals from the REFOCUS expert panels including 7 (58%) members of the BME virtual consultation panel commented on the preliminary Conceptual Framework. The comments ranged from suggested additions, to re-ordering of categories. As a result of the consultation, the definitions of the categories were refined, to make a clearer distinction between categories.

As only minor modifications from the Stage 1 preliminary Conceptual Framework were made, the final Conceptual Framework of Recovery, including all the categories which resulted from the 3-stage narrative synthesis process is included in Appendix 4.

3.3.1 Reflexivity

In line with the subtle realism perspective adopted within this thesis, throughout the systematic review and analysis I kept reflexive memos to record the impact of my previous knowledge and background on the development of the coding framework. This included any assumptions made about the importance of categories within the framework and especially within the sub-group analysis. Throughout the thematic analysis I was mindful that spirituality and religion were areas I felt, based on previous experience, would be particularly important to non-majority populations. Adding definitions, vote counting across all the included papers and having multiple coders were all techniques used to avoid pre-conceptions biasing the coding framework.

I was also aware throughout coding that the sub-group analysis represented a very heterogeneous group. The papers reported in the sub-group included individuals from a range of backgrounds, cultures and ethnicities. I was mindful of this throughout to reduce the chances of overstating and over-generalising the findings.

3.4 Discussion

3.4.1 Main results

The aim of the review was to increase the conceptual clarity regarding the meaning of recovery from the perspective of black individuals. A narrative synthesis approach was used to analyse the papers identified in the systematic search. From the narrative synthesis process, three overarching categories, namely Recovery Principles, Recovery Processes and Recovery Stages were identified. This thesis focused on the Recovery Processes.

The Recovery Processes were categorised into five areas: Connectedness, Hope and Optimism, Identity, Meaning and Purpose and Empowerment (CHIME). Each CHIME category included a number of subordinate categories which define and amplify the superordinate theme. Although there was a paucity of data, the sub-group analysis highlighted some differences in the meaning of recovery for people from minority ethnic backgrounds. Five areas of difference were evident in the analysis. These were a greater focus on spirituality and religion; overcoming stigma and discrimination including discrimination based on ethnicity, race and culture; culturally specific facilitating factors; additional mental health system level barriers and individualistic versus collectivist philosophical notions.

3.4.2 Strengths and limitations

Three strengths and four limitations can be identified.

Firstly, this was the first systematic review of conceptualisations of recovery using a method aimed at overcoming some of the criticisms of the recovery approach. In particular, adopting a transparent methodology addressed concerns regarding the current lack of rigour within the recovery literature [119,121]. Unlike traditional methods for evidence synthesis, narrative synthesis provides a novel and robust method for combining multiple study types. The approach allows for the systematic combination of qualitative and quantitative research studies, which fits with the mixed methods design within this thesis.

Secondly, this was the first systematic review to specifically focus on the perspectives of recovery for individuals from minority ethnic backgrounds. At present, issues of race, culture and ethnicity have largely been absent from the recovery literature [28,29]. This is consistent with the present review in which only 6 of the 97 included studies focused on non-majority populations.

The final strength was the robustness of the review. This was achieved by the inclusion of three different approaches to validating the framework: 1) double-rating of a proportion of papers to assess eligibility, 2) thematically analysing a sub-sample of medium quality papers to validate the initial thematic analysis and 3) expert consultation.

The first limitation of the review concerned the thematic analysis, which was a secondary analysis of published data. Consequently the analysis focused on the interpretations presented by the authors of the original papers. Our interpretations may have differed if conducting the same analysis using the primary data. The resulting framework should not be viewed as a definitive or rigid model of recovery. Instead it represents one interpretation of the available data. Despite this limitation, the review has produced a useable framework which was applied in remainder of the thesis.

A second limitation relates to the lack of available data assessing the meaning of recovery for individuals from black communities within the UK. As a consequence, the non-majority sub-group analysis represents a heterogeneous group of individuals and includes studies spanning a wide range of populations. It was felt that although belonging to very diverse populations, the participants included in the studies would share the common experience of being in a non-majority population, an experience that may have important implications for the meaning of personal recovery and mental health service use. Only one paper specifically focused on the meaning of recovery for black individuals within the UK, and within this paper only men were included.

The third limitation is that only English language papers were included in the review. Due to time and resource limitations it was not possible to translate papers for inclusion in the review. It is therefore possible that this inclusion criterion may have systematically excluded papers from non-majority populations. Future work could address this limitation by including all papers regardless of the published language, and assessing whether the Conceptual Framework remains a good fit for the data.

The final methodological limitation relates to the use of narrative synthesis to combine qualitative and quantitative studies. As discussed in Section 1.4.7, researchers have argued whether it is appropriate to combine data from studies which utilise and adopt different philosophical assumptions, including differences in ontology and epistemology [33]. However, the use of narrative synthesis is consistent with a subtle realism perspective, and is further

consistent with a mixed methods approach, which both Pope and Mays [33] and Creswell [48] have argued is a pragmatic approach to "real-world" mental health services research.

3.4.3 Links with the literature

In line with the MRC guidance for developing and evaluating a complex intervention, the systematic review and narrative synthesis was conducted in the early phases of the thesis in order to help develop the theory underlying the intervention. The findings of the present review can be linked to literature published since the original systematic search and narrative synthesis was conducted.

A study exploring the perceptions of 'wellness' in BME individuals at risk of developing psychosis was published after the review [164]. The study identified a set of definitions of wellness generated from the literature and from individual interviews. Twenty individuals recruited from an early psychosis team ranked the 50 identified definitions. Factor analysis indicated there were six factors important to the definition of wellness. These were: A sense of social purpose, Surviving God's test, Internalization of spirituality, Understanding and attribution of symptoms to witchcraft, Avoidance and adversity, and Seeking help to cope [164].

Although there was some overlap with the factors identified in the present review, particularly in relation to the importance of religion and spirituality, the study focused on people at high risk of psychosis, rather than those individuals who have used community mental health services for a range of time [164]. Consequently, there was still a need to investigate the perceptions of recovery for black individuals who use community mental health services.

An alternative approach to reviewing the literature was adopted by Weisser and colleagues, who assessed the meaning of recovery from a social inequities perspective [165]. Within their review, a purposive sample of papers was used to identify the degree to which current models of recovery addressed social inequities. The focus within each of the models of recovery included in the review was categorised into four groups. These were i) individual focus, ii) external/ structural barriers focus, iii) focus on the need for (culturally) appropriate services and iv) advocating for social inequities. Consistent with the findings of the present review, the authors concluded that the majority of papers focused on recovery at the individual level,

with less attention to collectivist understandings. Furthermore, the impact of inequality and inequity was not often considered within the research reviewed.

Finally, since conducting the original review, two further papers have been published which aimed to validate the Conceptual Framework [111,166]. The studies were conducted as part of the wider REFOCUS programme, with the thesis author a co-author of the first paper, and the lead author of the second. The first paper, focused on updating the systematic search and assessing country-wide differences in the meaning of recovery. The updated search followed the same review process as described in Section 3.2. Eighteen new papers were identified in the search, with vote counting (as described in Section 3.2.4) used to assess the frequency of the categories of the Conceptual Framework. Papers in the review were grouped based on country, with 11 countries represented in the analysis. Analysis of the vote counting by country, indicated that there was a similar distribution of coding for each of the five recovery processes [111,166]. Furthermore, the review highlighted how the literature was dominated by studies conducted in Anglophone countries such as UK, USA, Australia and Canada, with little research conducted in Asian and African countries.

The second paper focused on validating the Conceptual Framework through focus groups conducted with current mental health service users [111,166]. The paper focused on the concepts of validity and relevance (discussed in Section 1.4.3), and included a deviant case analysis which aimed to identify new themes not previously captured in the literature review. Overall, the focus groups indicated that the Conceptual Framework was both valid and relevant to people currently using mental health services within England. When discussing the experiences of recovery, all areas of the Conceptual Framework were present in the analysis.

3.4.4 Clinical and research Implications

The Conceptual Framework presented in this chapter has three main clinical and research implications.

Firstly, the findings of the Conceptual Framework relate to supporting recovery within mental health services. The review indicated that a range of areas and factors were important to an individual's personal recovery journey. This may mean that mental health services are required to take a boarder perspective in supporting people to live meaningful and hopeful lives, consistent with their hopes, goals and aspirations, in addition to focusing on clinical domains such as symptomatology and risk management. This includes considering areas that

are important to an individual's recovery such as spirituality, sexuality, education, friendship and the pursuit of life goals. Furthermore, a recovery-orientation could suggest that there is no longer the need to wait until the person is symptom-free before actively pursuing their goals. Instead, care should focus on using the person's strengths and resources whilst removing potential barriers to help the person achieve and pursue their own life goals, even within the presence of disability [114].

Secondly, the Recovery Processes provide a framework for assessing the effectiveness of clinical interventions aimed at supporting the recovery of people with mental health problems. The five CHIME processes provide a focus for potential interventions to target. Outcome measures could potentially measure the change in the areas of the Conceptual Framework when assessing effectiveness. Furthermore, the sub-group analysis suggests that certain areas, such as religion and spirituality or discrimination, should receive special attention to ensure recovery-focused interventions are applicable to black service users.

Finally, the categories of the Conceptual Framework could be used to guide the development of search strategies when conducting systematic reviews of the evidence base for recovery, and guide the indexing of papers within electronic databases. The term “recovery” was poorly specified in electronic databases, with qualitative research also poorly indexed. This meant that the present review had to adopt a two-stage cascading approach in order to identify relevant papers. The five CHIME Processes could be used as key terms and MeSH headings to enable future researchers to more easily identify relevant papers.

3.4.5 Implications for this thesis

The Conceptual Framework was used throughout the thesis to conceptualise recovery. Specifically there were four implications.

Firstly, the systematic review highlighted the need for further qualitative work to be conducted to understand the perspectives of recovery for people from black backgrounds. The review identified a gap in the evidence base in relation to understanding what recovery means to individuals from black communities within the UK. This provided the rationale for the qualitative exploration of recovery presented in Chapter 5.

The second implication was the use of the Conceptual Framework within the literature review of existing recovery interventions presented in Chapter 4. The Conceptual Framework

provided a empirically based theoretical framework, which was used to operationalise the term "recovery" throughout the thesis. Consequently, the Conceptual Framework provided a scaffold to identify and categorise interventions when reviewing the existing evidence base for recovery interventions.

Thirdly, the Conceptual Framework had implications for the design of the pro-recovery intervention described in Chapter 6. The Conceptual Framework was used alongside the Framework of Recovery Support developed in the qualitative section of this thesis (Chapter 5) to identify underlying recovery principles, which guided the intervention content.

The final implication relates to the evaluation strategy used within the cluster RCT (Chapter 7). The categories of the CHIME Recovery Processes provided a framework for selecting outcome measures for use in the RCT. This ensured that the outcomes measured within the trial had external validity and relevance, such that they matched the meaning of recovery for the population receiving the intervention.

3.5 Conclusion

This was the first systematic review and narrative synthesis aiming to provide conceptual clarity regarding the meaning of the term personal recovery. It was also the first review to specifically focus on the perspectives of individuals from non-majority backgrounds. The narrative synthesis process allowed both quantitative and qualitative evidence to be synthesised in a single and coherent analysis. The thesis-specific addition of a sub-group analysis of papers provided the rationale for further qualitative work to be conducted within the thesis.

Chapter 4 Recovery-orientated mental health services and interventions

4.1 Introduction

As highlighted in Chapter 3, the meaning of personal recovery varies between individuals. Consequently, there are potentially many ways to support personal recovery within and beyond mental health services. This chapter presents a literature review of the policy and evidence base for recovery-orientated services and interventions within adult mental health services.

This chapter has three objectives: i) to present an overview of exemplar evidence-based interventions which aim to support recovery, ii) to evaluate the evidence base for interventions aiming to support the recovery of black individuals and iii) to highlight common features of recovery interventions which have been culturally adapted for individuals from black backgrounds. The findings of the review helped to inform the development of the manualised pro-recovery intervention presented in Chapter 6.

A brief overview of recovery-orientated practice as applied to mental health policy is presented in Section 4.2. This is followed by a narrative literature review of interventions to support recovery in Section 4.3. Research into the use, effectiveness and adaptations of each intervention for black individuals is also discussed. The Conceptual Framework of Personal Recovery (Chapter 3) was then used to map the identified recovery interventions on to the five CHIME Recovery Processes in Section 4.4 to highlight the coverage of each process within the existing recovery interventions. Finally, the chapter presents a synthesis of common features of culturally adapted intervention in Section 4.5.

4.2 Recovery-orientated mental health policy

Before discussing the evidence base for the example recovery interventions, this chapter briefly considers the context in which the interventions are delivered. In many Anglophone countries a recovery-orientation is central to mental health policy. America, Canada, Australia, New Zealand and Ireland all have policy documents directly relating to the recovery-orientation of mental health services. For example, within the USA, personal recovery is mandated as the overarching operating principle of services within the President's New Freedom Commission on mental health [167] and the subsequent 'Federal Action Agenda' [168], whilst in Australia, the 'Fourth National Mental Health Plan of Australia', covering the

period 2009-2014 prioritises social inclusion and recovery [169]. Within England, a recovery-orientation has been apparent in mental health policy since 2001.

4.2.1 Mental health policy in England

As discussed in Chapter 2, the national mental health policy within England is *'No Health without Mental Health'* which was launched in 2011. The policy stresses that mental health is everyone's business and not just relevant to those with mental health problems [105]. Within the policy, good mental health and resilience are seen as more than just the absence of mental health problems, and are viewed as fundamental to other areas of life. These areas include physical health, education, employment, relationships and the economy. The policy includes two main aims summarised as improving the mental health and wellbeing of the whole population, and providing high quality mental health services. There are six objectives to meet these aims (as discussed in Section 2.8.3).

In relation to supporting recovery, the second of the six objectives states that "*More people who develop mental health problems will have a good quality of life - greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live*" [[105] p6]. Central to the policy is the governing principle that individuals who use services should be at the heart of them. This involves providing personalised care reflecting the needs of the person rather than the needs of the system or clinician, for example by providing people with information and support to allow them to make informed decisions about their treatment.

Within the NHS, the underlying principle for policy makers and commissioners is that of evidence-based practice. Evidence-based practice has been defined as the *"conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients... The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research"* [[170] p71]. The overall aim of evidence-based practice is to provide clinicians with the best-available evidence in a useable format to help inform clinical decision making alongside clinical expertise. Decisions about what is classed as the 'best-available' evidence correspond to the evidence hierarchy, whereby different types of evidence are given primacy over others. The evidence hierarchy shown in Figure 4.1 is advocated by the NHS and positions systematic reviews of RCTs at the top with expert opinion and case reports at the bottom.

Figure 4.1: Evidence hierarchy

Although definitions of personal recovery stress the unique and personal nature of the journey, evidence-based practice prioritises group-level knowledge [171]. The drive towards evidence-based practice has increased the necessity for recovery research to adopt more rigorous and transparent methodologies, as one of the common criticisms of the recovery movement has been the lack of a scientific evidence base [119,172]. As discussed above, evidence from systematic reviews and RCTs is prioritised within the NHS over non-experimental designs and qualitative experience. This difference has led to an epistemological tension between giving primacy to the experience of the individual and conforming to the scientific community and proponents of evidence-based practice. This relates to the tension between idiographic or subjective knowledge and nomothetic knowledge, which focuses on objective phenomena and the development of laws. However, as Barber argues, stressing personal recovery within services does not necessarily point to the abandonment of evidence-based medicine [113]. Consistent with this view, an empirical evidence base for interventions which support recovery is becoming apparent. The present thesis aimed to further develop this evidence base for recovery interventions by testing the efficacy of a team-level pro-recovery intervention within a cluster RCT.

4.2.2 Clinical Guidelines

Linked to the predominance of evidence-based practice, the provision of mental health treatment and services in England are guided by the National Institute of Health and Care Excellence (NICE) treatment guidelines. Guidelines are based on the principles of evidence-based practice and recommend interventions alongside good practice points for individuals working within mental health services.

Traditionally clinical guidelines have been organised around diagnostic categories, for example Clinical Guideline Number 1 recommended treatments and services for the care of people with schizophrenia and related disorders [173]. However, more recent guidelines include a transdiagnostic focus. Of particular relevance to recovery within the UK was the 2011 service user experience guideline *'Improving the experience of care for people using adult NHS mental health services'*. The overarching aim of the guidance was "*to promote person-centred care that takes into account service users' needs, preferences and strengths*" [[174] p6]. The focus on transdiagnostic guidelines and the shift towards recovery within guidance and policy, further strengthens the rationale for conducting an RCT of a pro-recovery intervention.

4.2.3 Organisation Programmes to support recovery

To support the development of a recovery-orientation within mental health services, an organisational approach to supporting recovery has been adopted. The Department of Health commissioned the National Centre for Mental Health and NHS Confederation's Mental Health Network to pilot a national programme which aimed '*to test the key features of organisational practice to support the recovery of those using mental health services*' (Department of Health 2011, p22 cited in [172]). The programme, known as Implementing Recovery through Organisational Change (ImROC), prioritises a process of cultural change instead of service transformation, and emphasises the adoption of recovery values at all levels of the mental health system. ImROC is based on ten key organisational challenges. The ten organisational challenges included ensuring organisational commitment, increasing personalisation and choice and redefining user involvement [117,175,176,177].

4.3 Interventions to support recovery

The chapter now presents a literature review of example interventions to support personal recovery. There are potentially many diverse ways to support an individual's recovery, which may or may not include 'professional' and/or mental health service-based interventions [112]. It was beyond the scope of the thesis to review all interventions, instead selected

interventions are included. The inclusion criteria used by Slade and colleagues was applied [178]. Specifically, as the Conceptual Framework developed in Chapter 3 identified five Recovery Processes, interventions were required to focus on one of more of the CHIME Recovery Processes to be included in the review. Furthermore, the interventions were required to have emerging or established evidence for their effectiveness based on empirical investigation.

Eight interventions were included in the review as illustrative examples. The eight interventions represented different levels of the socio-ecological framework. Briefly a socio-ecological framework views an individual within their particular context and stresses the importance of identity at the intrapersonal, interpersonal, community (including mental health services) and societal levels. The eight interventions included in the review were Wellness Recovery Action Plans (WRAP), Illness Management and Recovery (IMR), Peer-Support, Hearing Voices Groups, Strengths-Based Case Management (SBCM), Psychosocial Interventions (e.g. CBT, Family Intervention), Interventions to support Spirituality and Anti-Stigma interventions. Figure 4.2 highlights how the eight different interventions map onto a socio-ecological framework.

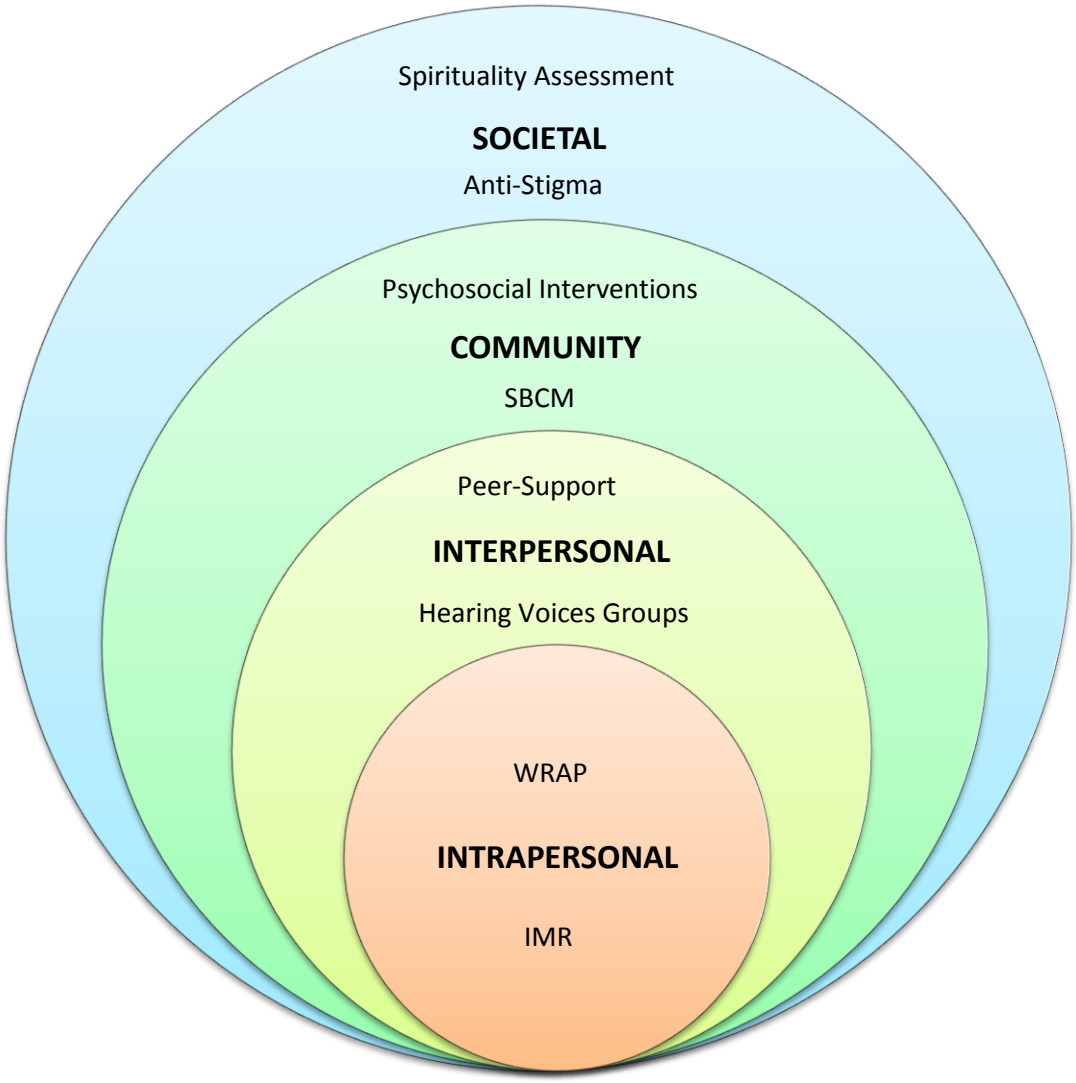


Figure 4.2: Recovery interventions as mapped onto a socio-ecological framework

4.3.1 Intrapersonal Interventions

The two interpersonal interventions included in the review are both types of self-management interventions. Self-management interventions typically focus on methods and skills by which individuals can effectively learn to manage, monitor and cope with their condition or symptoms. In the context of mental health problems, interventions have targeted outcomes such as empowerment and hope, alongside clinical outcomes including reduced hospital admission and relapse rates [179].

Intervention 1: Wellness Recovery Action Plans (WRAP)

A central component of mental health services within the UK is the provision of care plans which primarily focus on clinical and functional outcomes such as symptom levels, risk and unmet need. In contrast, care plans which focus on wellness and recovery as opposed to deficits and symptoms may be one approach to supporting an individual's personal recovery.

A key premise of a recovery-focused approach to care planning is to allow those experiencing mental distress to take responsibility for their own wellness, manage and reduce their mental distress and learn new coping mechanisms and skills including the utilisation of existing strengths and resources [180].

WRAP developed by Mary Ellen Copeland, is an evidence-based strategy to help enable individuals to monitor their own symptoms and use planned responses to eliminate or reduce distress [181]. These techniques include i) developing personal wellness strategies, ii) creating daily maintenance plans for dealing with day-to-day pressures and stressors, iii) recognising the early warning signs of symptoms and their triggers and iv) creating crisis plans and post-crisis supports to aid both clinical and personal recovery. Within WRAP, information is also included about how the individual wishes others to respond in times when they are unwell, particularly at times when symptoms make it difficult for the person to make decisions or stay safe [180]. To help individuals develop their WRAP plans, WRAP training packages have been developed, which include facilitated discussion and exercises, often facilitated by individuals with lived experience of mental health problems.

Two RCTs (reported in four papers [182,183,184,185]) and three quasi experimental studies [186,187,188] have been conducted into the effectiveness of WRAP for people with severe mental illness. The majority of these studies focused on WRAP training for individuals with mental health problems, with one study also delivering training to mental health staff [187]. A range of outcomes have been assessed including hope, quality of life, empowerment and symptom levels. Across the two RCTS, positive and consistent outcomes of WRAP have included a significant reduction in service utilisation and unmet need [184], significant improvements in hope and increases in quality of life [182,183,185]. However, findings for the impact of WRAP on symptom levels and overall recovery have been mixed, with one of the two RCTs failing to find a significant difference between the two groups on both outcomes [184].

The non-RCT evidence has broadly supported the RCT findings. Across the three non-randomised studies, WRAP was associated with significant improvements in symptom levels, hope and recovery attitudes. As with the RCT data, findings for overall recovery were mixed [188].

Evidence for the effectiveness of WRAP for black individuals

With reference to the effectiveness of WRAP training for people from black backgrounds, only two exploratory studies have been conducted within the UK. Both of the studies did not quantitatively assess service user outcomes, but did provide qualitative data regarding the effectiveness, feasibility and acceptability of WRAP interventions. The two studies conducted within the UK included an evaluation of WRAP training for a group of women from BME backgrounds within Glasgow [181] and a DRE initiative conducted in Northamptonshire Healthcare NHS Trust [189]. Details and findings of the two projects are now reviewed. To meet objective three of the review (i.e. common cultural adaptations) recommendations or cultural adaptations detailed within the two studies are presented in Box 4-1.

Within the Glasgow study, seven women from black backgrounds attended WRAP training. Data from the pre-training focus groups and interviews indicated that participants identified with the notion of personal recovery and could list factors which supported them. The focus groups identified a number of cultural issues which would need to be addressed within the WRAP intervention. These are outlined in Box 4-1. Post-training data collection indicated that individuals were engaged in the process and valued the opportunity to use their own lived experience within the sessions to discuss strategies for staying well [181].

The second project assessing WRAP was conducted in Northamptonshire Healthcare NHS Trust. The project aimed to engage members of the Somali community to develop their own Wellness Recovery / Resilience Action Plans. Within the project, 30 individuals from the Somali community received WRAP training. In addition to helping individuals manage their own wellness, the project aimed to enable individuals to help others within their community. The WRAP training provided was culturally adapted to better fit with the cultural belief systems of the participants [181].

The initial evaluation of the programme indicated a high level of satisfaction with WRAP and the training process. In particular, training raised awareness of mental wellbeing within the targeted communities, improved partnership working and developed meaningful engagement with individuals. Following the project one community leader noted *"We cannot count by words with both verbal and in writing how for the last three months of WRAP and peer-support training has really made a difference within our community. It's the introduction of the WRAP that changed our perception towards mental health and the people with mental illness."* [[189]p.12].

Within the two WRAP studies a number of adaptations were made to the intervention to ensure it was culturally appropriate. These are outlined in Box 4-1.

Adaptation 1: Explicitly including discussion around stigma, discrimination and racism within the intervention and training.

Adaptation 2: Discussing the person's status within society such as immigrant, asylum seeker or refugee and the impact this has on the person.

Adaptation 3: Ensuring the intervention was consistent with cultural beliefs around illness, including explanatory models such as spiritual or magical causes.

Adaptation 4: Training and the intervention focused on collectivist elements such as the community and/or the family.

In addition to the above four intervention adaptations a number of recommendations were made by participants during the evaluation stages. These included:

Recommendation 1: Issues concerning personal privacy and the stigma of mental illness within the community need to be addressed.

Recommendation 2: The language used within the intervention should be adapted to make sure it is culturally relevant.

Recommendation 3: The intervention should place less emphasis on individualistic concepts such as self-advocacy and personal responsibility and more on the role of the family and support within the community.

Recommendation 4: Training should be delivered to BME only groups.

Recommendation 5: A “one size fits all approach” for recovery interventions should be avoided within mental health care.

Box 4-1: Cultural adaptations and recommendations - WRAP

Intervention 2: Illness Management and Recovery (IMR)

IMR, which was developed by Mueser and colleagues [190] is a standardised psychosocial intervention and approach to self-management. The intervention has been designed for people with severe mental illness and focuses on teaching individuals to manage their condition and achieve personally meaningful goals. Topics covered include recovery, practical facts about mental illness, building social supports, using medication effectively, coping with stress, and reducing relapses [190,191,192].

IMR has been evaluated in empirical studies including three RCTs, which have been summarised in a systematic literature review [193], alongside non-randomised evidence. The narrative summary of the RCTs indicated that individuals assigned to IMR had greater improvements in recovery knowledge and attitudes, significantly reduced self-reported symptoms, better social functioning and increased quality of life. However, there was no effect of IMR on rates of hospitalisation, employment or changes to medication. The three quasi-experimental and three pre-post studies corroborated the findings of the RCTs showing increases in personally defined recovery, and significant decreases in symptom levels [193].

Recent research developments for the IMR approach have included a positive RCT assessing the implementation of the approach within acute care and inpatient settings with individuals waiting to be discharged [194] and IMR delivered as a computerised intervention [195].

Evidence for the effectiveness of IMR for black individuals

Although the US studies have included a diverse range of participants including individuals from African-American backgrounds, no empirical research has specifically focused on the effectiveness of IMR for black individuals. Furthermore, the IMR literature has not assessed the cultural acceptability of IMR for black individuals, with only one evaluation assessing the cross-cultural adaption of IMR within Japanese inpatient settings [196].

4.3.2 Interpersonal Interventions

Two types of interventions at the interpersonal level were included in the review, namely Peer-Support and Hearing Voices Groups.

Intervention 1: Peer-support interventions

The involvement of people with lived experience in the care and support of others using services was identified in the Conceptual Framework as an important component of an individual's recovery. Policy documents within Anglophone countries all encourage the implementation and increased availability of peer-support services. The term peer-support is an umbrella term which includes many different interventions, from peer advocacy and mutual self-help groups through to peer-run mental health services. Despite differences in terminology, a number of elements are common. These include highlighting positive stories of people with lived experience, increased visibility of role models to promote hope and operating principles which promote personal recovery [25].

Peer-support has one of the most robust evidence bases for recovery interventions [178]. The effectiveness of peer-support services has been assessed within at least four systematic reviews [197,198,199,200]. Two of the reviews included a range of study designs such as RCTs, quasi experimental and qualitative investigations. Within these reviews the evidence was narratively synthesised [197,200]. Results from the two reviews indicated that peer support is associated with positive outcomes such as increased service satisfaction, improved general wellbeing and improved quality of life. However, the majority of positive outcomes were reported in the descriptive and non-controlled studies, with the evidence from comparative and RCT studies less conclusive. For example, the findings from the seven RCTS reviewed by Repper and Carter were inconclusive regarding rehospitalisation, empowerment, quality of life and symptom levels [200].

Two further systematic reviews have focused exclusively on the RCT evidence with the aim of conducting a meta-analysis [198,199]. This included a Cochrane review which assessed the efficacy of employing service users as providers of care [199]. Eleven RCTS involving 1796 individuals were included, five comparing service users to mental health professionals and the remaining six comparing mental health services with or without employed consumers. The results of both meta-analyses indicated that there was no significant differences in outcomes between the peer and non-peer conditions in terms of quality of life, depression, service satisfaction and general mental health symptoms, although there was a slight reduction in crisis and emergency service use for people receiving consumer-provided care [199].

The final review was conducted within the context of the NICE psychosis treatment guideline. The review spilt the peer-support interventions into three groups namely peer-led mental health services, peer-support specialists and mutual self-help groups. Results across the three groups were mixed with most outcomes failing to show a significant difference between the peer-support intervention and standard care. However, there was some evidence for positive effects of peer support on measures of personal recovery and hope.

Peer-support for black individuals

Despite the relatively large evidence base, empirical studies assessing the impact and cultural acceptability of peer-support for black individuals within the UK are currently lacking. Although empirical investigations into the effectiveness of peer-support groups have not been specifically conducted with black individuals, there have been empirical investigations of culturally tailored peer-support interventions for other minority ethnic individuals, including

African-Americans. Tondora and colleagues conducted an RCT of a peer-based person-centre care approach for African Americans and individuals from Latino backgrounds [201]. Their aim was to develop a culturally-responsive person-centred intervention which utilised recovery coaches to assist people in their own recovery journeys. The cultural adaptations made to the intervention are shown in Box 4-2. Although the preliminary findings of the trial have been published, quantitative data relating to the outcomes is unpublished at present.

Within the grey literature, there are frequent reports of projects which have been set up to deliver peer-support services to members of BME communities, including UK-based projects. Many of these services are set up and run by voluntary sector organisations within the community. A survey with nine peer-support services, including three which were specific to BME individuals was conducted by Faulkner and colleagues in 2012 [202]. The survey highlighted a range of benefits for peer-support in general which included helping people find a voice, developing a mutual understanding within the group, reducing social isolation and increasing access to support and information. In addition to these general recommendations, a number of recommendations related to the provision of services for individuals from minority groups are outlined in Box 4-2.

Adaptation 1: Ensuring that the intervention assessed culturally relevant experiences. This included assessing spirituality and spiritual experiences and discussing discrimination based on race, culture and/or ethnicity.

Adaptation 2: Ensuring that the language used throughout was culturally appropriate. This included being receptive to colloquialisms.

Adaptation 3: Ensuring a collectivist approach was taken to include relationships with the community and family.

Adaptation 4: Ensuring the diversity of staff members, including ethnic matching in some cases and in others providing staff with training in cultural competency.

Recommendation 1: Ensuring that peer-support services remain diverse and that individuals have access to a range of services, including BME and non-BME specific services.

Box 4-2: Cultural adaptations and recommendations - Peer-support

Intervention 2: Hearing Voices Groups

Hearing voices groups provide individuals with a chance to meet, share and discuss experiences with other people who also hear voices. Common components of the groups

include targeting beliefs about voices, promoting coping strategies, increasing social skills and activities to help improve self-esteem [203].

Although there is a currently emerging empirical evidence base for hearing voices groups, published quantitative evidence is more limited. Ruddle and colleagues narratively reviewed the quantitative and qualitative literature for HGVs [204]. Two quantitative studies, one investigating an unstructured HVG within a pre and post-test design [205] and another utilising a problem-solving approach [206,207], were included in the review. Results of both studies indicated that participation in the groups was associated with increased empowerment, self-esteem and coping strategies. There was also a significant reduction in hospital bed days and overall numbers of hospital admissions. Positive changes were also observed for the frequency and perceived power of voices.

Qualitative findings evaluating the mechanisms of change within hearing voices groups have suggested that individuals benefit from the reduced social isolation of attending a group-based session, the exchange of coping strategies and that by sharing their stories, the experiences are to a certain extent normalised. Groups also provided individuals with a safe-space, often outside of mental health services, where they could discuss their experiences (Martin 2000 cited in [204]).

HVGs and black individuals

At present, none of the studies assessing the effectiveness of hearing voices groups have been conducted specifically with individuals from black backgrounds.

4.3.3 Community Level Interventions

Although recovery for some individuals can occur outside of mental health services, the focus of this thesis is on developing and evaluating an intervention within NHS community mental health services. Consequently, the two interventions (Strengths-based Case Management (SBCM) and psychosocial interventions) included as examples for the community level, focus on interventions delivered within mental health services.

Intervention 1: Strengths-based Case Management (SBCM)

In contrast to traditional mental health services which typically focus on deficit amelioration, a strengths-based approach centres on the amplification of strengths, talents and abilities [208]. A systematic review into strengths assessments conducted as part of the REFOCUS

programme (described in more detail in Section 6.3.1), identified the evidence base for SBCM for people with severe mental illness. The aim of SBCM is to prioritise the individual's strengths to overcome deficits and to actively promote the acquisition and use of resources. SBCM is led by the service user and focuses on the relationship between staff and service users.

Studies of SBCM include two RCTs as well as four quasi-experimental designs. A range of recovery and clinical outcomes have been assessed within these studies including social support, goal setting and attainment, relapse and hospital admission [208]. Within the two RCTs [209,210], SBCM was consistently associated with improved social interaction, community living skills and increased vocational training. There was evidence for SBCM reducing hospital admission as well as improving physical and mental health including symptom severity. However, there was no significant difference between SBCM and standard case-management in terms of service satisfaction and measures of social support [209,210].

The findings from the four quasi-experimental studies, which included a pre and post design as well as a cohort study, broadly corroborated the RCT findings. In particular, SBCM was associated with reduced symptom severity, improved quality of life and vocational outcomes. However, the findings regarding hospital admission, community integration and daily living skills was inconsistent with the majority of studies showing improvements from baseline to follow-up, but failing to demonstrate a significant difference in the change scores between SBCM and standard care groups [211,212,213,214].

SBCM for black individuals

The evidence for SBCM predominantly emanates from the US, with no published empirical studies conducted within the UK. Although the above studies often included a proportion of individuals from African-American backgrounds, the effectiveness of the intervention within this sub-group of participants was not assessed, nor was the cultural acceptability of the intervention.

Intervention 2: Psychosocial evidence-based interventions

Despite representing a diverse range of interventions and approaches, psychosocial evidenced-based interventions such as CBT were included within the review due to their importance within policy and guidelines. Although these interventions are not traditionally seen as coming from a recovery-orientation as they were instead developed within the context of evidence-based practice, they can be used within a recovery-orientated service [115]. For many people, evidence-based interventions such as supported employment [215], CBT [216] and family intervention [217] are important to a person's recovery [115]. Bellack also emphasises that current evidence-based treatment guidelines and recommendations are consistent with recovery principles and a recovery-orientation within services [218]. For instance, Individual Placement and Support focuses on the attainment of competitive employment, which for many is consistent with a recovery approach, especially in achieving meaning and purpose in life.

Due to the clinical origins of these interventions, studies assessing the effectiveness of these strategies have typically focused on related clinical outcomes such as symptom reduction, hospital admission and relapse rates (e.g. [219]) instead of recovery outcomes and processes such as hope, identity, empowerment and meaning, as was the criteria for inclusion within this literature review. More recently however, researchers have begun to assess the impact of psychosocial interventions on recovery outcomes [220,221], in addition to developing recovery-focused psychosocial interventions. Hodgekins and Fowler conducted an RCT of a social recovery-focused version of CBT [221]. The intervention focused on improving the hours spent by the person in structured activity, and also aimed to reduce feeling of hopelessness and improve self-esteem. Results indicated that the recovery-focused CBT intervention was effective in reducing hopelessness and increased the individual's positive attitudes towards themselves and others. Furthermore, improvements in recovery processes mediated the relationship between improvements in activity and the intervention. Additionally, a study is currently ongoing which assesses the impact of a recovery-focused CBT intervention for people with a first episode of bipolar disorder. Within the intervention, CBT is tailored to introduce a recovery-orientation to service users, with the development of recovery plans included as exercises [222].

Culturally adapted psychosocial evidence-based interventions for black individuals.

Two psychosocial evidence-based interventions which have been culturally-adapted specifically for black individuals within the UK were included in the review. These were

culturally adapted CBT for psychosis [223] and the Cares of Life intervention for depression and anxiety [224].

Research has previously shown that individuals from black backgrounds have higher dropout rates and poorer outcomes within CBT studies compared to white participants [225]. In order to develop a culturally sensitive intervention, Rathod and colleagues conducted individual semi-structured interviews with people with schizophrenia, focus groups with lay members of minority ethnic communities, and interviews and focus groups with mental health staff including CBT therapists. The qualitative data indicated that the intervention could be culturally adapted to better suit the needs and explanatory models of illness adopted by individuals from minority populations [225]. These adaptations are outlined in Box 4-3.

Individuals with psychosis were randomly assigned to receive either 16 session of culturally adapted CBT for psychosis (CaCBTp) or treatment as usual and were assessed pre, post and six months following the intervention. Results indicated that individuals assigned to the CaCBTp arm showed significant reductions in symptom measures, including positive symptoms and depression compared to the control arm (Between group difference in total symptoms =11.31, 95%CI 0.14 – 22.49, p=.047). Furthermore, satisfaction with treatment was significantly correlated with the number of treatment sessions attended. However, although showing benefits in terms of clinical outcomes, the researchers did not assess personal recovery and recovery related outcomes such as hope or empowerment, nor did the study compare culturally adapted CBT with standard CBT [226].

The second psychosocial evidence-based intervention to be discussed is a needs-led community based intervention - Cares of Life. The intervention aimed to improve the outcomes for individuals from black backgrounds with common mental health disorders. Emphasis within the intervention was placed on helping individuals achieve in key aspects of their life such as employment or social functioning. The model used by the service followed a stepped-care approach and was delivered by community health workers who were ethnically-matched to the participants. The content of the intervention was pragmatic and focused on the needs of individuals, but typically included advice, advocacy, health education and brief psychosocial interventions such as CBT and solution-focused therapy. Twenty individuals were assigned to the intervention and compared to 20 individuals randomly assigned to a wait-list control who received only information about local mental health services. The results indicated that individuals in the intervention significantly improved in measures of depression

(mean group difference = 7.76, 95%CI 0.86-14.65, p=.03) There were no differences however in levels of general functioning between the groups [224]. Recommendations and adaptations for Cares of Life are presented in Box 4-3.

Adaptation 1: Ensuring the intervention and therapeutic model used was consistent with cultural beliefs of the individual. This included understanding and exploring the cultural beliefs and values of the person.

Adaptation 2: Ensuring that culturally appropriate language was used.

Adaptation 3: Placing a greater emphasis on collectivist identities including the role of the family and community.

Adaptation 4: Understanding and exploring the illness beliefs of the person including their explanatory models.

Adaptation 5: Explicitly discussing issues concerning stigma, discrimination and racism.

Adaptation 6: Ethnic matching of staff delivering the intervention, including the use of community development workers.

Box 4-3: Cultural adaptations and recommendations - psychosocial evidence-based interventions

4.3.4 Societal-Level Interventions

The final level of the socio-ecological framework is the societal level. Within the review, interventions to support Spirituality and Anti-Stigma Interventions were included.

Intervention 1: Interventions to Support Spirituality

A common theme within the qualitative literature focusing on service user experiences is the importance of spirituality and religion, an area often ignored within mainstream mental health services [25]. New approaches to incorporating spirituality within assessments and therapies have started to gain empirical validation [227]. Current research has included discussing the feasibility of incorporating spiritual themes into religiously-orientated mindfulness cognitive therapy. Within the CBT intervention, religious beliefs and frameworks of understanding mental health distress are explicitly included. Anecdotal and individual case reports have noted positive benefits. However, formal evaluation of this approach, and in particular religiously-orientated mindfulness CBT have yet to be published, although research evidence has highlighted positive benefits of mindfulness-based CBT in general [228].

Studies have also assessed the acceptability of spiritual assessments as implemented by psychiatrists within the context of current mental health service provision. Huguelet and colleagues conducted an RCT comparing individuals who were randomised to receive either a spirituality assessment in addition to standard care, or standard care alone. Results indicated that individuals using the service had a high interest in discussing religion and spirituality [229]. Furthermore, the assessment was viewed as acceptable and led to a significantly better rate of attendance compared to those receiving standard care assessments ($t=-2.45$, $df=1$, $p=.02$). However, there was no difference in recovery scores or satisfaction with services, although service-user interest in the assessment was high.

Interventions to support spirituality and black individuals

The evidence base for interventions to support spirituality within mental health care is at present in its infancy, with no studies specifically focused on black individuals.

Intervention 2: Anti-stigma interventions

The Conceptual Framework of Recovery highlighted the impact that societal stigma has on a person's recovery. Internalising the stigma associated with mental health problems has been linked to a reduction in empowerment and lowered self-esteem [118].

Over recent years, empirical interventions have been developed which aim to reduce community-wide and societal stigma, particularly amongst young people. Predominantly these interventions have focused on three approaches; i) educational lectures and information, ii) video-based media and iii) social contact with individuals with lived experience. A narrative review of mental health awareness interventions aimed at reducing societal stigma amongst young people identified forty studies of which 15 were RCTs. Results of the review indicated that direct social contact with people with mental illness was the most effective method of changing attitudes towards mental health problems [230]. Interventions have also tackled stigma amongst health care professionals, with one RCT demonstrating that both a DVD about service users' experiences and a live lecture were equally as effective at changing attitudes and knowledge amongst student nurses [231].

Anti-stigma interventions and black individuals

As with interventions to support spirituality, evaluations have not specifically focused on the effects of anti-stigma interventions for black individuals, within the context of mental health.

4.4 Synthesis of interventions to support recovery

The Conceptual Framework of Personal Recovery presented in Chapter 3 identified five key processes of personal recovery from mental illness. The interventions reviewed above can be categorised based on the five recovery processes and the match between the processes and the primary aims of the intervention. This mapping exercise is shown in Table 4.1.

Table 4.1: Recovery intervention mapped on to the CHIME framework

Intervention	Connectedness	Hope and Optimism	Identity	Meaning and Purpose	Empowerment
WRAP		X			X
IMR		X			X
Peer-support	X	X			X
Hearing Voices Groups	X			X	X
Recovery-based CBT		X	X		X
SBCM		X	X		X
Spirituality Support			X	X	
Anti-stigma		X	X		X

Table 4.1 details the current coverage of the CHIME recovery processes within existing recovery interventions and highlights how most interventions currently focus on a few recovery processes, predominantly hope and empowerment.

4.5 Common features of culturally-adapted recovery interventions

The review highlighted that the evidence for supporting the recovery of black individuals is currently lacking. The review failed to identify an empirical evidence base for cultural adaptations for the majority of interventions. Only WRAP, culturally-adapted CBT for psychosis and Cares for Life had been adapted and evaluated with individuals from black background within the UK, with IMR and peer-support culturally adapted for BME groups outside of the UK.

As discussed in Section 4.1, the third aim of the chapter was to synthesise the evidence for any culturally adapted interventions to identify common features. The cultural adaptations and/or recommendations throughout the review were included in Box 4-1 to Box 4-3. These adaptations and recommendations were organised into 10 categories and are presented in Table 4.2. The themes were grouped into two over-arching categories: identity and service delivery.

Table 4.2: Cultural adaptations and recommendations

Theme	Description	Intervention(s) including theme	Used within thesis?
Aspects of Identity			
The impact of stigma, discrimination and racism	Many of the interventions explicitly included discussions around the impact of stigma and discrimination. This could include discussions of mental health stigma and discrimination within society and the individual's community as well as societal stigma and discrimination surrounding race, culture and ethnicity. Many interventions provided a safe space for discussions of racism to take place.	WRAP Peer-support CBTp	Yes
Collectivist identity	Interventions frequently adopted a collectivist approach to identity including understanding the role of the family and the community. This included raising awareness of mental health problems and treatment within the community.	WRAP Peer-support CBTp	Yes
Religion and spirituality	Interventions needed to acknowledge the importance of spirituality and religion.	WRAP Peer-support CBTp	Yes
Status	The status of the person within society was recommended. In particular, the impact of asylum seeker or refugee status was mentioned.	WRAP	No
Understanding the person's cultural background	It was important that clinicians delivering the intervention got to know the person and their cultural background. This included understanding their values and how these might have an impact on their treatment.	WRAP Peer-support CBTp Cares of Life	Yes
Understanding the person's illness perceptions and beliefs.	Interventions were mindful to the different illness beliefs that individuals may have. This could include beliefs about	WRAP Peer-support	Yes

Theme	Description	Intervention(s) including theme	Used within thesis?
	spiritual and social causes of illness.	CBTp	
Service -delivery			
Ethnic-matching	Matching the ethnicity of staff delivering the intervention to the ethnicity of the person receiving the intervention or service.	Cares of Life Peer-support	No
Avoiding a "one size fits all approach"	It was important that the intervention avoided a one size fits all approach by assuming all members of a BME group wanted and needed the same treatment. Interventions needed to be adapted to the needs of the individual.	WRAP Peer-support Cares for Life	Yes
Ensuring language is culturally appropriate	The language used throughout the intervention needed to be culturally appropriate. This could include using idioms of distress which were consistent with the culture of the person.	WRAP Peer-support CBTp Cares for Life	Yes
BME-specific groups	Within some studies there were suggestions that the training, interventions or services provided should be BME specific and only open to individuals from BME backgrounds.	WRAP	No

4.6 Implications for thesis

The literature review has four implications for the thesis, three of which relate to the design of a new manualised pro-recovery intervention and one which relates to the implementation and evaluation of that intervention.

Firstly, a new pro-recovery intervention is needed. The literature review highlighted that although there is an emerging evidence base for interventions which support recovery, there is a lack of evidence for the effectiveness and cultural acceptability of recovery-based interventions for individuals from black backgrounds. This lack of evidence for existing interventions provided the rationale for developing a new manualised pro-intervention within this thesis.

Secondly, the new pro-recovery intervention developed needed to address the five CHIME Recovery Processes. The synthesis of recovery interventions suggested that the recovery interventions tended to focus on selected areas of personal recovery such as empowerment, or hope. Interventions addressing all five processes included in the Conceptual Framework were lacking. The main implication of this finding was the need to take a broader perspective when developing the new intervention. This was to ensure that the new intervention would match the Conceptual Framework and address the needs of black individuals who use mental health services.

The third implication of the review was the identification of seven common themes of culturally adapted interventions which were used to guide the development of the pro-recovery intervention. The seven themes apparent in three or more of the interventions and taken forward within this thesis were i) explicit discussion of stigma and discrimination including the impact of racism, ii) focusing on religion and spirituality iv) taking a collectivist approach including the family and community, iv) ensuring language is culturally appropriate, v) understanding the person's cultural background vi) understanding the person's illness perceptions and beliefs, and vii) avoiding a *"one size fits all approach".*

Fourthly, mental health policy within Anglophone countries is broadly supportive of a recovery-orientation. However, the review highlighted that current mental health policy and decision making is guided by the principles of evidence-based practice which prioritises RCT evidence over other study designs, including qualitative data. The lack of currently available

RCT evidence for recovery interventions, particularly for black individuals provided the rationale for evaluating the intervention within an RCT.

The implications of this chapter and the previous two literature reviews on BME mental health needs (Chapter 2) and the meaning of recovery (Chapter 3) were addressed in the remainder of this thesis. Firstly a qualitative study which aimed to understand the meaning of recovery as well as what supports the recovery of black individuals was conducted (Chapter 5). This was followed by the development of a recovery-focused intervention, model and manual (Chapter 6) which was evaluated within a cluster RCT (Chapters 7 and 8).

Chapter 5 Framework of Recovery Support

5.1 Introduction

This chapters reports the findings of the main qualitative study conducted as part of this thesis. As discussed, the Conceptual Framework of Recovery identified a gap in the current knowledge base regarding the perception of recovery for black individuals. Only one paper included in the review focused on individuals from black backgrounds [150]. This lack of evidence provided the rationale for a new qualitative study to be conducted.

In addition to the lack of evidence regarding the perception of recovery, the literature review of existing recovery interventions presented in Chapter 4 highlighted a lack of empirical evidence for the effectiveness of existing recovery interventions for black individuals. This provided the rationale to develop a new pro-recovery intervention within this thesis. In line with the MRC framework, in order to develop an intervention to support the recovery of black individuals, the meaning of recovery needed to be explored. Ford and Harawa recommend that when designing any intervention, particularly if culturally adapted, researchers should actively involve people in the design phase to ensure that the concepts under study and the intervention developed are culturally appropriate [13].

5.1.1 Aims and objectives

To address the gaps in the literature, the aim of the study was to develop a Framework of Recovery Support for black individuals.

This aim was addressed through two objectives.

Objective 1 (Meaning of recovery) was to understand the meaning of recovery including the barriers and facilitators of recovery.

Objective 2 (Recovery support) was to identify the types of support and services that individuals feel would support their recovery.

5.2 Method

5.2.1 Design rationale

Two sub-studies were conducted and are reported in this chapter. Sub-study 1 consisted of focus groups and Sub-study 2 individual semi-structured interviews. Using two methods to gather data allowed for methodological triangulation [232], as the methods differed in the

breadth and depth of data collected. Focus groups were used to gain a breadth of opinions and a group perspective on the meaning of recovery. The individual semi-structured interviews built upon the emergent themes from the focus groups, and included more in-depth personal stories of recovery. The interviews involved a mix of people who had and had not been in focus groups. Including focus group participants allowed for direct questioning regarding the meaning of certain aspects the participants had discussed in the focus groups, and included deviant cases whereby an individual disagreed with the group perspective voiced [233]. Using individuals who had taken part in the focus groups also allowed for the emerging framework from the analysis to be tested with interview participants. The aim of this respondent validation was to improve the validity and relevance of the emerging framework [33]. Including new participants provided triangulation of the findings of the focus groups and ensured the comprehensiveness of the data and theoretical saturation.

5.2.2 Sample

Five focus groups were planned. For each focus group the aim was to recruit six to eight participants, which represents the optimal number to ensure each participant is given adequate time to discuss their view point, whilst creating a group dynamic [234]. A convenience sample of black individuals who use community mental health services was recruited for the focus groups. Although primarily a convenience sample, a sampling frame was designed to increase variation in the participants included in the study. The sampling frame was designed to include participants who had used mental health services for different lengths of time as well as individuals using different types of community teams such as assertive outreach, early intervention services and recovery teams. Individuals also varied in whether or not they attended BME-specific services. A diverse range of participants were sought to ensure a breadth of option and diversity within the experiences reported.

A total of fifteen individual interviews were planned. In addition to five individuals who were recruited from the focus groups, a convenience sample of individuals was recruited for the remaining interviews. Recruitment continued until category saturation was achieved, whereby any new data can be easily captured within the existing categories, all of which have been fully explored [235].

For both sub-studies, the inclusion criteria were i) individuals who self ascribe their ethnicity as black, black African, black Caribbean, African Caribbean, black British or black other; ii) currently using (or have previously used in the past 6 months) adult community mental health

services which utilised the Care Programme Approach (CPA); iii) aged between 16 and 65; iv) able to understand and speak English; v) well enough to participate as rated by their clinician and vi) willing and able to discuss their experience of recovery from mental health problems.

For Sub-study one (focus groups), in sites where there was a low proportion of eligible individuals, the inclusion criteria were extended to include individuals from Asian and mixed race backgrounds (where part of the individual's identity was identified as black). It was anticipated that broadening the inclusion criteria would ensure there were enough potential participants for each focus group.

5.2.3 Setting

Across the two sub-studies individuals were recruited from four different NHS Trusts: South London and Maudsley NHS Foundation Trust (SLaM), Leicester Partnership NHS, 2gether NHS Foundation trust (in Gloucestershire) and Tees Esk and Wear Valley NHS Trust (TEWV).

SLaM is the largest mental health trust within the UK, with over 100 sites including both urban and suburban settings and an annual income of £330m. Four and a half thousand staff members are employed in approximately 300 teams to provide adult mental health services to four London boroughs (Croydon, Lambeth, Lewisham and Southwark). Over 34,000 individuals currently receive adult mental health services from SLaM. This population is ethnically diverse, with 37% of individuals recorded as either "Black African", "Black Caribbean", "Black British" or "Black other" on the clinical information system. Recently, SLaM has been reorganised to provide services through Clinical Academic Groups (CAGs), which aim to bring together research and clinical practice. SLaM was the main site for the thesis work including the cluster RCT reported in Chapter 7.

The three other Trusts included in the qualitative study were a mix of urban, semi-rural and rural locations. Leicester Partnership NHS Trust provides a range of health and wellbeing services for people living in Leicestershire and Rutland. The service integrates both learning disabilities and mental health and employs almost 6,000 staff across these services. 2gether NHS Foundation Trust provides specialist mental health and learning disability services to a population of 761,000 in Gloucestershire, Herefordshire and the surrounding area. A total of 2,300 staff members provide care to individuals with 96% of services provided within the community. TEWV provide mental health, learning disability, eating disorder and substance misuse services to the 1.6 million people living in the North East of England. Around 5,700

staff members working in approximately 170 sites in a geographic area covering costal, rural and industrial regions.

For Sub-study 1 (focus groups), participants were recruited from SLaM, Leicester and 2gether. An additional focus group, which recruited participants from two voluntary sector BME organisations in South London - FANON and Southside Partnership Trust, and the Maroon Centre - was held in SLaM. The trusts were chosen to maximise variation in terms of urbanicity, mental health service configuration and demographics of the area including ethnic density and socioeconomic status. Individuals were recruited from the two voluntary sector organisations to ensure a breadth of perspectives within the study, including the perspectives of individual who may have disengaged from traditional statutory sector services.

Participants included in Sub-study 2 (interviews) were primarily recruited from SLaM and from the same two voluntary sector organisations discussed above. Five individuals who took part in the focus groups and an additional eight new participants were recruited from SLaM. As a focus group was not possible due to the low number of people meeting criteria on the caseload within TEWV, an additional interview was conducted within the trust to ensure the participant's views could be included in the study.

5.2.4 Topic guide development

Topic guides were created for each sub-study. To ensure that the interview and focus group questions were based on the language of the participants, a number of interviews available on healthtalkonline (www.healthtalkonline.com) were analysed using content analysis. All nine available interviews looked at the experience of mental health problems for people from BME communities. A particular focus was placed on identifying the language and phrases used by participants when describing their experience of recovery. From the analysis, it was apparent that individuals more commonly used terms such as "wellness" and "wellbeing" when discussing their recovery. Furthermore, people tended to talk about their "mental health experience" rather than a specific mental health problem or mental illness. This information was used to ensure that the questions and follow-up prompts were all phrased in understandable and culturally appropriate language.

The topic guide for the focus groups included four main areas:

1) What does recovery or wellness mean to you?

2) How has your community mental health worker/team helped or supported you in your recovery?
3) What about the ways that your community mental health worker/team doesn't help or support you in your recovery?
4) What could your community mental health worker/team be doing differently to better support your recovery?

For each question a number of follow-up probes such as 'Why has that helped' or 'Why is that important' were included in the topic guide.

The structure of the topic guide reflected the group dynamics typically observed within focus groups. Tuckman [236] proposes that a focus group will typically go through four stages.

1) Forming - in which the group comes together and is starting to form as a group but getting to know one another.
2) Storming – many of the groups processes are trialled in this stage of group development, with different members vying for leadership
3) Norming – during this stage an agreement or norm is reached about how the group functions and,
4) Performing – the group is now operating at its most effective.

Therefore focus group questions addressing the main research aims were asked in the middle of the focus group following a number of warm-up questions designed to get the group talking and to allow them to progress through the first three stages identified above. The topic guide is shown in Appendix 5.

The topic guide for the individual interviews aimed to gather in-depth data relating to the personal experience of recovery and is shown in Appendix 6. Five main sections were included in the topic guide:

1) Personal stories of recovery including the meaning of the word from the individual's perspective
2) What helps and hinders recovery or being well
3) The impact (both positive and negative) of mental health services on an individual's recovery
4) Should mental health services be any different, including suggestions as to how a person could be better supported.
5) The dream question around an individual's goals and aspirations.

Each section contained a number of questions and follow-up prompts which asked individuals to give examples or stories of their experience. Prompts for each question made use of the themes which had emerged from the focus groups. Additionally, individuals who had taken part in a focus group were asked to elaborate on examples they had given during the focus groups.

The topic guides for the two sub-studies were sent out for consultation with the BME virtual consultation panel (described in section 1.5.1). Six (50%) of members responded. As a result of the responses, the prompts in both topic guides were adjusted to make explicit reference to race, culture and ethnicity, racism and discrimination. The panel suggested that this would give permission to participants to discuss these sensitive issues with a researcher from a white ethnic background.

Both the focus group and interview topic guides were revised iteratively based on the concurrent analysis of the transcripts. This ensured that categories in the emerging frameworks could be fully explored in subsequent interviews and that the language remained appropriate throughout.

5.2.5 Procedure

For each trust a Clinical Studies Officer (CSO) helped recruit participants for the focus groups. The CSO publicised the focus groups by attending team meetings of eligible community teams. Participants were also identified through the use of posters and information leaflets distributed to the participating NHS trusts, and displayed at day centres run by the two voluntary sector organisations.

For Sub-study 2 (interviews), participants who had taken part in the focus groups were contacted by the researcher via the phone. New participants were recruited into the study using posters and contact with staff working within statutory and voluntary sector services.

For both sub-studies, eligible participants were sent an invitation letter with an information sheet about the study. All interested participants were contacted by the thesis author and telephone screening conducted to ensure they met the inclusion criteria. The thesis author also spent time at the two day centres run by the voluntary sector organisations to enable potential participants to ask any questions about the study and become familiar with the researcher.

Two facilitators conducted each focus group. The thesis author acted as the main facilitator responsible for asking the majority of questions. A user-researcher co-facilitated three of the four focus groups. The role of the co-facilitator was to listen to the responses of the group and note anything warranting further exploration. The co-facilitator also provided support to the main facilitator and assisted with prompting the group throughout the session.

Before starting the focus group, informed consent was obtained from all participants and information about demographics and service use collected via a standardised sheet. The focus group began with the researchers welcoming participants to the group and outlining the purpose of the research. Participants were given details about the consent process and given the opportunity to withdraw from the study. Issues surrounding confidentiality were discussed, with the group given adequate time to ask any questions. It was stressed that although interested in the experience of the participants, group members did not have to answer any questions they were uncomfortable with, and that they were free to withdraw at any time. Participants were then given a number of ground rules in line with those suggested by Morgan [234]. The ground rules stressed the importance of every member's opinion. This was further emphasised by the use of prompts which asked if anyone had any other or different opinions to those being expressed.

The focus group was structured around the topic guide. As far as possible the facilitators used prompts from the participants to maintain the flow of the conversation and to enable an open discussion. The focus group remained flexible, however the pre-determined prompts were used if the group lost focus or diverted from the research question. Both facilitators used a conversational style throughout.

Each focus group lasted a maximum of 90 minutes. At the end of the session participants were given the opportunity to ask any questions and reflect on their experience. All participants received £20 for their participation.

Following the focus groups both facilitators individually engaged in a reflexive activity to record their initial impressions of the session, and then came together to discuss these notes. Emergent themes and notes taken during the group were also discussed. The aim of the reflexive exercise was to assist with the data analysis and to allow any modifications to be made to the topic guide.

During the phone conversation to organise the individual interviews, participants were given the choice of being interviewed either by the thesis author or by a black interviewer. One individual out of the 14 requested and had their interview conducted by a black interviewer. All other interviews were conducted by the thesis author. Prior to participation, informed consent was obtained from all participants. The researcher and participant then discussed the purpose of the interview, the consent process and issues surrounding confidentiality. Participants were given adequate time to ask questions before filling in a standardised sheet regarding demographic and service use data. Throughout the interview it was stressed that individuals did not have to answer any questions they were uncomfortable with, and that they were free to withdraw at any time.

The interviews started with the researcher asking a set open-ended question relating to the individuals personal experience of recovery. This was followed by prompts building on the participant responses. Where possible the interview was flexible, however, some pre-determined prompts were used if the participant lost focus at any point. All questions and prompts were asked in a conversational style rather than a formal question and answer format.

The interviews lasted a maximum of 60 minutes. At the end of the interview participants were given the opportunity to ask questions and reflect on their experience. Participants received £10 for their participation. Up to 15 individual interviews were initially planned, but data collection ceased after 14 interviews as category saturation was achieved.

All interviews and focus groups were conducted at local voluntary or statutory sector properties and were recorded using two digital audio recorders. Data were transcribed verbatim and anonymised.

5.2.6 Analysis

Transcripts were coded using nVivo qualitative data analysis software version 9. Thematic analysis was used for the data analysis. Thematic analysis refers to the process of identifying patterns or themes within the data. Although many methods of qualitative data analysis, such as grounded theory or Interpretative Phenomenological Analysis, include the identification of themes, within this thesis thematic analysis can be considered a distinct analysis method. The

thematic analysis conducted for this thesis followed the guidance of Braun and Clarke [144]. Six iterative phases in the process of thematic analysis are proposed:

1) The reader becomes familiar with the data by transcribing, reading and re-reading the transcripts, keeping reflective memos and taking notes.

2) Initial codes are generated from the data. This involves the identification of interesting and meaningful portions of text and occurs equally across the whole data set.

3) Broader overarching themes within the data are identified from the initial open codes. Codes may be merged or split, and the relationships between codes identified.

4) The researcher further refines the overarching themes by splitting or collapsing codes and themes with similar and overlapping meaning. Within this stage, a definition for each theme is generated. This stage also involves the development of a coding framework or thematic map which aims to capture the relationships between themes. Transcripts are read and re-read to ensure that any new codes previously missed are now identified.

5) A final refined coding framework is produced through further defining and naming each of the themes. This coding framework can then be applied to the entire dataset.

6) The final stage involves writing up and reporting the analysis.

An inductive open coding approach was adopted. During the first stage of coding, the transcripts from both the interviews and focus groups were read and re-read, with meaningful fragments of text identified. These were coded as free nodes within nVivo. To ensure that the codes remained consistent, coherent and distinctive, each new code was checked against those already coded using a constant comparison approach [144,237]. Codes were constantly checked against the original data to ensure fidelity to the inductive and data-driven approach. Following initial open coding, a process of interpretative coding was applied [237,238], whereby the researcher organised the codes into themes by pruning and merging codes with similar meanings [239]. During interpretative coding, themes were organised into hierarchical categories based on the properties of each theme and their relationships with other themes. Initially, open coding focused on the semantic level of the text, with the subsequent interpretive coding going beyond semantics and the surface meaning of the text to consider the latent meaning inherent in each code [144]. A definition was created for each code to ensure consistency of coding between the transcripts. The language of the original data extracts was used to inform the headings and definitions of each category within the framework [144]. As part of the interpretive coding phase, a coding framework was created, with a core category identified within the data.

Throughout the coding process, memos were created to capture the thought processes and ideas as they developed. These memos contained ideas about the relationships between the codes as well as details of the emerging framework. In keeping with a subtle realism epistemology (see Section 1.4.3), memos also recorded ideas and instances where the researcher went beyond the surface meaning and interpreted the latent meaning of the text. The memos recorded after each interview and focus group were used alongside the transcripts during the analysis to help provide details of the context.

Example of a theoretical memo:
"The central theme throughout the interviews and focus groups is that of identity. The mental health problem is often expressed in terms of identity and what it means to the person and their sense of self. Part of the recovery process is overcoming this threat to identity. Within the system and society the person is faced with threats to their identity, including discrimination and racism. Rebuilding or regaining a positive sense of identity seems to be important to all, whether this is becoming the same person as before the mental illness, or developing and becoming a new person. In some circumstances this is made harder by staff, the system and society. It also questions whether people from already disadvantaged and undervalued groups can consider themselves truly recovered".

Example of a reflexive memo:
"One of the things I noticed in the interviews and focus groups is that often you get different responses. It appeared from the focus groups that a lot of people wanted BME specific services as this was a topic frequently discussed. However, looking more closely at the data, it comes down to a few individuals who felt this way. I interviewed those people, who expressed a strong interest and preference for BME services, and also interviewed other people in the groups who were perhaps silent at this point or who disagreed."

To improve the reliability of coding, a second rater independently coded a proportion of the focus group and interview transcripts. Following coding, both rates meet to discuss the basic codes and discussed the development of the framework. Both coders agreed on the core category and discussed the relationship of other themes within the core category. Any differences in coding were discussed and recorded, which helped to highlight alternative interpretations of the data and any underlying assumptions each coder may have brought to the analysis [239].

5.3 Results

Twenty-six participants took part in four focus groups and 14 individual interviews were conducted until category saturation was achieved. Individuals used a range of statutory and voluntary sector mental health services. Five interview participants also took part in the focus group study. Characteristics of the sample are shown in Table 5.1**.**

Table 5.1: Characteristics of the sample (n=40)

Characteristics	Focus Groups	Individual Interviews
N	26	14
Gender (N, %):		
Female	11 (42%)	8 (57%)
Male	15 (58%)	6 (43%)
Age (Mean, SD)	41.2 (12.4)	41.9 (10.8)
Ethnicity (n, %):		
Black/ Black British - African	10 (38%)	5 (36%)
Black/ Black British - Caribbean	7 (27%)	5 (36%)
Black Other	1 (4%)	1 (7%)
Asian / Asian British – Indian	2 (8%)	0
Asian / Asian British - Pakistani	1 (4%)	0
Mixed race	1 (4%)	3 (21%)
Other	4 (15%)	0
Diagnosis (n, %):		
Psychosis	3 (11%)	1 (7%)
Schizophrenia	5 (19%)	4 (29%)
Schizoaffective disorder	6 (23%)	0
Bipolar Disorder	1 (4%)	3 (21%)
Psychotic depression	2 (8%)	1 (7%)
Depression	2 (8%)	2 (14%)
Other	2 (8%)	2 (14%)
Did not want to disclose	5 (19%)	1 (7%)
Mental health team type (n, %):		
CMHT	2 (8%)	0
Support and recovery	9 (35%)	4 (29%)
Early intervention service	3 (11%)	1 (7%)
Assertive outreach	3 (11%)	0
Home treatment team	0	1 (7%)
Forensic	1 (4%)	1 (7%)
Rehabilitation	1 (4%)	1 (7%)
Continuing care	3 (11%)	3 (21%)
Other	2 (8%)	2 (14%)
Did not want to disclose	2 (8%)	1 (7%)
Time in MH services years (mean, SD)	9.0 (6.1)	11.2 (7.8)
NHS Trust (n, %):		
SLAM	19 (73%)	13 (93%)
Gloucester	2 (8%)	0
Tees, Esk and Wear Valley	0	1 (7%)
Leicester	5 (19%)	0

The core category within the analysis which was linked to all other themes and sub-themes was 'Identity - (re)gaining a positive sense of self'. The first and second order categories included in the coding framework are shown in Box 5-1, with the full coding framework included in Appendix 7.

Core category: Identity - (re)gaining a positive sense of self

1.Defining the self

- 1.1 Multiple dimensions and identities of a person
- 1.2 Comparisons with others
- 1.3 Having a strong identity

2.Negative sense of self

- 2.1. Societal level threats
- 2.2. Illness as a threat to identity

3.Continuum of recovery - from returning to the same as before to becoming a new person

- 3.1 Returning to the same as before
- 3.2 Recovery is about change – becoming a new person
- 3.3 Meaning of recovery depends on meaning of illness

4. Mental health System level facilitators of gaining a positive sense of self

- 4.1 Being treated as an individual
- 4.2 Support from the right services and professionals
- 4.3 Staff as a facilitator of a positive identity

5. Facilitators of a positive sense of self beyond the mental health system

- 5.1 Individual / intrapersonal level facilitators of a positive identity
- 5.2 Connecting with people - interpersonal facilitators of a positive identity
- 5.3 Community and societal level facilitators of positive identity

Box 5-1: Coding framework

5.3.1 Core category: Identity - (Re)gaining a positive sense of self

The core category throughout the analysis was identity and in particular gaining a positive sense of self. Often the mental health problem was expressed in terms of identity and what it meant to the person's sense of self. Regaining a positive sense of identity was key to recovery regardless of whether the person saw themselves as having a mental health problem, or whether they still had symptoms. Gaining or in some cases regaining a positive sense of self included having a strong identity, high self-esteem and generally feeling good about your sense of self. The way the person felt they were perceived by and within society was also important.

Often participants implied regaining a sense of identity, with particular emphasis on phrases such as *"I came back"* [SLaM FG2, male], or *"I returned"* [SLaM FG1, female]. This suggested that the person had in some way gone away or changed. In this sense, the process of recovery was seen as returning either to your former self, or becoming better than before.

"For someone to actually say 'Look, there could be something wrong with you' and I don't know, just trigger something in me like, 'Well, I'm sick' it's like when you have the flu, it's like 'I've got to get well'….. The real meaning of recovery I think it's to be almost perfect like your original self or even better than your original self." [SLaM FG2, male]

For many even the word recovery was synonymous with gaining something back:

"Because for me, when you talk about recovery, you're talking about regaining something. It's the 're' in front of it, if you redo something that means, regaining a sense of self of worth and stuff like that." [SLaM FG1, female.]

Although the focus groups and interviews were organised around the barriers and facilitators of recovery, the majority of themes in the analysis related to how the person felt as an individual, be it in an individualistic or collectivist sense. Many of the barriers to recovery were threats to the person's sense of self, such as staff making assumptions, societal level racism and discrimination, or lack of opportunity. On the other hand, facilitators of recovery involved fostering and developing a positive sense of self. For example, becoming an empowered individual was important to many. Being treated as an individual and having your story heard was a central theme and acted as a key determinant of whether individuals felt services supported their recovery.

Within this core category, five superordinate categories were included and are now described.

5.3.2 Category 1: Defining the self

Part of regaining a positive sense of self was being able to define your identity. People had different ways of defining themselves which may or may not include their diagnosis. For many participants their diagnosis or mental health problem was not the most important element of the person, despite services and treatments often being organised around this feature. For some people their identity was defined in terms of their social roles, and most notably by work and occupation. Having something to do each day, and being a productive member of society helped people to define themselves:

"I think that recovery comprises a lot of different things... I mean, one thing that's really important to me is work, yeah, I think that as Marx said, work defines us as people. And, without doing something useful every day you can start to forget who you are, basically" [Leicester FG, male]

As with the concepts of ethnicity and culture (discussed in Section 1.2.1), identity was not fixed but was instead fluid and changeable. This was captured in the first subordinate category "Multiple dimensions and identities of a person" which relates to the different identities one assumes in different social situations and contexts.

Category 1.1: Multiple dimensions and identities of a person

Participants described their identity in terms of multiple dimensions or elements. These dimensions could be described by a socio-ecological framework, which views the person in their particular context and stresses the importance of identity at the intrapersonal, interpersonal, community and societal levels [235].

> *"Because we're not made up of just like a physical entity or two dimensions or whatever, we're many dimensions."* [Interview 3, female]

At the intrapersonal level, people would describe their identity in terms of their occupation, their likes, dislikes, skills and talents. Individuals described what made them unique. People also recognised that their identity changed over time, and what was important to them at one point in their life, might not be as important in their future. This contrasted with the experience of diagnosis. For some, the focus on diagnosis within services meant that individuals felt as if they were being labelled or *"placed in a box"* [Leicester FG, female]. Once given the label, it was hard to move on, despite making progress in other areas of their life:

> *"I had a tribunal about a month ago and they said the same thing that '[P10] doesn't accept that she has schizoaffective disorder for the rest of her life' whereas I do accept it I just don't accept the being ill part of it. You shouldn't have to be ill for the rest of your life. There's more to the person than that."* [Interview 10, female]

At other levels of the socio-ecological system, individuals talked about their identity in spiritual and religious terms, such that being a religious person defined at least part of their identity. Religion was one source of belonging and gave individuals meaning. In some cases this reflected a more collectivist view of identity, where identity was defined in terms of the family, community and social roles. The idea of giving back to others in your family as well as contributing to both the community and society were important elements of a collectivist identity.

"It is important to me to help other people and helping them at the same time as enjoying helping... I want to help people do things, do things which are enjoyable in their life." [Interview 6, male]

However, for most individuals their identity was not strictly individualistic or collectivist. Instead, identity was made of different elements of each. For example, individuals would see themselves in terms of their community but also as a unique individual within that community.

Category 1.2 Comparisons with others

Part of developing and defining a positive sense of self was making social comparisons with others. Individuals frequently made both upward and downward comparisons, where they compared themselves to people in better and worse positions respectively. In many cases, people made downwards comparisons between themselves and other service users. Individuals in the study saw themselves as very different from other people with mental health problems, particularly those in hospital. Furthermore, participants described how hospital should be reserved for people who were really *"mad" "insane"* or "*a danger to society"* [2gether FG, female]. In this sense such a downward comparison helped to boost the person's self esteem and reduce self-stigma.

"They took me to the mental hospital and started to leave me all day with the people who are really mentally ill and I was not mentally ill, I was sane and I was alright. But when I saw the others, believe me, I thanked God for what I have and that it's not me like them, because I started to say have you put me in hospital because I am mad? But when I saw the others around me, I found they are mad, not me." [2gether FG, female]

Comparisons with others also helped to normalise the experience of mental illness. Realising that you were not the only one to experience certain symptoms and interacting with people who had gone through similar occurrences could help individuals come to terms with their own experiences.

"I thought I was the only one. There are organisations where people can come and just gently work through things with each other, they have sessions, talking therapy, so we talk out our problems and get ideas off each other when we need some type of help to help us grow, to manage, to understand to deal with our problems. Um, yeah, so, I think those type of things can help you recover" [Interview 9, male]

Participants often made use of metaphors and similes to describe and normalise their experiences, such as making comparisons between mental health and physical health. The use of metaphors and similes helped individuals to couch their experience in familiar terms, which reduced the threat the experiences posed and helped to normalise the experience.

> *"If it was a physical thing and I was a 100 metre runner and I could run in 9.5 seconds for me to recover from an injury would mean that I would be running 9.5 seconds again. So in terms of mental health I think it means a similar thing."* [Interview 12, male]

Category 1.3: Having a strong identity

Finally, when defining the self, individuals talked about the importance of having a strong identity. This identity could be individualistic, collectivist, incorporate the illness or be distinct from the mental health experience. What was crucial however was that the identity assumed was a strong identity. Characteristics of a strong identity included being able to tell your story, feeling empowered, having a greater understanding of yourself and connecting with roles models and success stories.

For most participants, it was important to have interactions that enabled the person to connect with their background and to help them have a stronger sense of identity, particularly at times when they were unwell or struggling within the mental health system. This could include having connections with people who have undergone similar experiences, both in terms of mental illness and/or societal level racism and discrimination.

> *"I need to have some connection that I come from strong people. Because I don't feel strong, I need to have some connection with someone who knows about struggle? I need to have some connection with someone who knows about all the discrimination my family had to go through, that I had to watch and how that shaped the way I think and feel."* [SLaM FG1, female]

Roles models, particularly those from black communities, and success stories were another positive source linked to a strong identity. This gave people hope of success and resulted in people feeling proud that they belonged to a black background. Role models were perceived as individuals who had overcome the negative consequences of societal stigma and discrimination to achieve and prosper, and helped the individual deal with any experienced or anticipated societal stigma.

"You have the African Americans in Hollywood, Denzel Washington, Wesley Snipes Beyonce and all that, you see that Hollywood films it soon goes for me I'm like that. I really looked at myself and I said 'If I was born again, I wanna be black such united colour' Yeah I'm so glad I'm black. It's a universal, a mahogany so you should never be ashamed of it. I'm so glad I'm black! you know, I love my colour ". [SLaM FG1, male]

However, not all role models needed to be from the same background. For some hearing about others in recovery, particularly with the same diagnosis acted as role models, regardless of their race, culture and ethnicity. Having recovery role models gave people a sense of hope, and a feeling that despite a diagnosis or label, a meaningful life was possible.

"My probation officer was a woman who was bipolar. She was actually quite good in the way that she kind of explained to me that 'I've been through everything a bipolar person goes through, but if, I still manage to hold down a career, so you can have a label, it doesn't matter' and that gave me hope" [Leicester FG, male].

In order to develop and communicate this strong sense of identity, individuals needed the chance to tell their story, this not only helped them to understand their experiences, it made the person feel as if they were treated and valued as an individual.

"I had this new social worker and she sat down next to me the first day in my flat and she goes 'So um, tell me all about your illness then. Tell me what happened to you'. And I just looked at her in shock. Because I never had anybody ask that. I says 'What do you mean? It's all in my files' she goes 'I want to hear it from you, from your point of view'. I've never ever heard anybody care about me like that." [SLaM FG 2, female]

5.3.3 Category 2. Negative sense of self

Individuals described how recovery involved overcoming the negative impact of having a mental health problem. This included the negative effects of low self-esteem, self-stigma and societal discrimination. Participants expressed this idea as an overwhelming negative sense of identity. Within the framework, this category included two main sources of threats to identity: "societal level threats" and "illness as threat to identity".

Societal level threats included how the person viewed, and was viewed by society. This included the perception of being a black person within a white society, and/or coming from an already disadvantaged background. The second category, "Illness as a threat to identity" acknowledged the often negative and disastrous effect that mental health problems can have

on an individual's sense of self. This including threats to identity from within the mental health system, including the impact of having a diagnosis, mental health stigma and the community's reaction to mental illness. The experience of the illness itself, and the negative identity some people attached to having a mental health problem was coupled with the societal threats to identity. The impact of these different threats to identity resulted in a multiple stigmatised identity, which for some individuals created an identity crisis.

> *"There are some African people who don't want to be African...part of their problem is that they've got an identity crisis and they don't really want to be treated as an African person anymore"* [Interview 9, male]

Category 2.1 Societal level threats

In order for individuals to gain a positive sense of self, the societal threats to identity needed to be overcome. The societal perspective was particularly important, given that individuals frequently experienced society as holding a negative attitude towards black people.

> *"We do live in a Caucasian system and a lot of us do face a lot of racism. We face it all the way through school, we faced it in our job, we faced it in the community, we even face it in the mental health system."* [SLaM FG 2, male]

One of the themes related to how certain struggles and attitudes within society were played out again and experienced within services. For instance, many individuals felt a sense of oppression within society, and often talked about an unequal power distribution with white people having more power and financial capital. This same unequal power distribution was frequently played out within services, particularly where the majority of psychiatrists and senior staff members were from white communities. Some participants termed this experience "black struggle", and went on to detail the impact this has on their identity.

> *"I see white people as just having all this power and when I've tried to challenge the power it's not been good for me, it's broken me, I don't just want a black person in a white system who doesn't recognise me or where I come from."* [Interview 2, female]

> *"It is harder yeah, but even without mental illness, things are hard for black people to progress.... It goes back a long long way, it goes back years when black people were not welcome in Britain and things were set in progress and they're still in progress today and it's the unsaid that is keeping black people on the lower in terms of mental health and in prisons.* [Interview 13, male]

Furthermore, being an individual from a minority ethnic group seemed to accentuate the stigma of mental illness, as the person often viewed themselves as belonging to multiple stigmatised groups.

> *"With me with discrimination I've noticed now, whites say 'Oh is he a Jamaican?' and some Africans will say 'He's a Jamaican' and I get it from some of the Jamaican lads 'Oh he's a Nigerian' like that. As a black person, even in a black service, I get it all ways you know? And then we have mental health stigma when we go back to work. 'You're mad!' You can't win"* [SLaM FG1, male]

The position of general disadvantage extended beyond race, culture and ethnicity to also include lack of employment opportunities and poverty. Individuals suggested that in order for people to recover there was a need to take a look at wider society. People could not be expected to recover if they are already living impoverished and disadvantaged lives.

> *"And it's just not being addressed by people in these services. They spend money everywhere, they spend thousands on teaching us to rap and write poetry, when some of us don't even have fridges, or proper homes to live in, or a proper social network or anything yeah, it's ridiculous".* [Leicester FG, male]

This need to address wider issues of disadvantage, inequality and poverty in society included for many the adequate provision of practical support and employment advice, in addition to the emotional support available within services.

> *"We need people to sort out our benefits, sort our jobs, some people it might be the place where they're living, some people it might be just, something they've got to pass by their house every day. That might be the thing that makes them breakdown, this needs sorting".* [Interview 13, male]

Finally for some people to recover there was a need to be treated and valued as a British citizen. Being treated as an outsider caused the individual to experience further mental health problems and contributed to their deteriorating negative sense of self.

> *"I wasn't treated as if I was a British citizen, I was just treated as if I was a nobody and 'why are you sick, get out of here'. That sort of treatment. I felt all of that added to my sickness, which got worse, not better."* [2gether FG, female]

Category 2.2: Illness as a threat to identity

The second category included in "Negative sense of self" related directly to the experience of mental illness. Individuals described how having a mental illness was a threat to their sense of integrity. People talked vividly about the negative experiences they had gone through, and of the chronicity of mental illness. People described *"feeling trapped", "feeling hopeless about their future", "life as a living hell"* and feeling as if they would *"never accomplish anything again"*. These negative experiences resulted in low self-esteem and a negative self image.

> *"I don't know but in most cases you feel low self-esteem about yourself or any other type of fall which causes deteriorations in yourself so I just really believe recovery is about getting up and trying to find yourself again."* [SLaM FG 2, female].

For some people when they experienced symptoms and distressing events, they no longer recognised themselves. Individuals described how their friends, family and community treated them differently because they had a mental health problem. In nearly all cases, this differential treatment had a negative impact on the person's sense of self-worth.

> *"Well it makes me feel really uncomfortable, when I tell people and they're like, they make... I don't know, just their personality goes all cold on you and you know their facial expression, their personality, everything just goes all funny."* [Interview 3, female]

The negative illness experience also included the way people were treated by services and the interactions they had previously experienced with mental health staff.

> *"When the illness struck, I had to give up, I resigned from my work. I lost my house because I can't pay the mortgage. Plus I'm suffering, and then now, when I go to some of these places to get some mental health services, they treat me like a moron"* [SLaM FG1, male]

Some participants describe how when in hospital they were left feeling powerless as decisions were taken away from them. Information was often lacking or not communicated effectively at a time when the individual was highly distressed. These encounters were described as dehumanising, and could have been improved by a few simple actions such as welcoming the person, bringing them in during the night, or even just offering them *"a cup of tea".*

> *"As soon as you arrive at the hospital the power is taken away from you. They give you industrial hard medication what changes the body, changes the chemistry in your mind so straight away I feel they do damage. The first thing they should do is give you some counselling sessions, welcome you with a cup of tea but instead as soon as you*

step through the door, they asked for my name, wrote my name down on a piece of paper and gave me two blue tablets" [interview 10, female]

Many of the themes centred on services as traumatic and disempowering. In particular, involving the police and ambulances not only increased the fear for the person but left the community fearful of mental health services. This promoted the idea that mental health services are coercive and another *"form of control*".

"The thing that I would change about the service is to have patients brought in hospital only at night, rather than in the afternoon or the morning. It's very intimidating and embarrassing having to see your neighbours and people in the street seeing you being taken to the ambulance or police car and thinking 'What's this person done?', 'What's going on?' You know, it's not very nice." [Interview 3, female]

Once in services, individuals noted that staff often made assumptions about them which related to ethnicity or culture, such that a one-size fits all approach was evident. This was experienced as a loss of individuality.

"I think sometimes they put people in a big bowl you know? So in Leicester there's a lot of Asian people... So when I go to the BME things it's Asian and there's no blacks there. There's still something missing for black African people. They sort of say 'Oh well, we've provided an Asian group, so we've covered BME'. The BME they talk about is Asian, and I'm not Asian." [Leicester FG, female]

This one size fits all approach was coupled with a lack of communication, where staff members did not discuss the individual's values and treatment preferences, but instead made assumptions on behalf of the person. For example, one individual describes an experience of an assumption in relation to accessing a BME-specific service.

"We have [service name] which is a black group. And on a Tuesday, it's only for black people and the white people are not allowed to come in, which I think is wrong. I feel bad, I feel terrible for the other people. Because I used to go before and one time, a white person, my friend came in and they said 'You're not allowed in' and she said 'Why?' 'This is for black ethnic group' and she took it offensively and walked out. I felt bad so I didn't go anymore." [Interview 1, female]

Staff members and mental health workers also made assumptions about the person's beliefs and value systems. This could included cases where the service user and staff member shared some part of their cultural or ethnic background.

> *"I remember the first time I was in hospital, the nurse asked me if I had voodoo, if there's some people making me ill from home, from Africa. It was an African nurse. So I said 'that's not in our interest and experience'.* [SLaM FG1, male]

Coupled with these negative service experiences, individuals also frequently described negative interactions with specific staff members which included themes such as *"a lack of communication", "not listening", "lack of trust within the relationship"* and *"disrespect",* all of which left the individual feeling disempowered and devalued.

It wasn't just the distressing experience of mental health services that had a negative impact on identity. Participants talked openly about the ways they viewed people with mental health problems prior to their own difficulties and how this resulted in self-stigma. This led to a sense of isolation as people did not want to talk to their peers within the community about their experiences for fear of the same stigma and discrimination.

> *"Before brushing with the mental health system, I lived around this area.. How society sees people who have mental health is something that you grow up with... you just look at a person and dismiss them, they're mad… So that is how when I first had my experience of it, those were the things that brought stigma to my attention."* [Interview 12, male]

Furthermore, individuals did not want to tell people about their mental health problems due to reactions they had experienced, even if they saw themselves as well on the way to recovery. This was seen in sharp contrast to physical health problems, which people found easier to talk about.

> *"Because I go to places and I mix with people, and a lot of the time I don't tell them I've had a mental health problem and to me that is not part of recovery. Because if I've broken my leg, I could just tell everyone 'Oh I broke my leg'. I can't go out there and just walk into a party of people well dressed, drinking champagne and go 'Yeah, I'm a paranoid schizophrenic'*. [SLaM FG2, female]

5.3.4 Category 3. Continuum of recovery - from returning to the same as before to becoming a new person

The process of recovery involved moving from this negative sense of self, to gaining or rebuilding a positive sense of identity. Gaining a positive sense of identity was important to all, regardless of whether this was returning to the same person as before, or developing and becoming a new person. Linked to this, was the meaning of the illness experience. In particular, the meaning of the illness experience had implications for the meaning of recovery and the type of help people wanted and/or expected. Three subordinate categories were included in this over-arching category.

Category 3.1: Returning to the same as before

For some people regaining a positive sense of identity was about returning to the same person as before. This meant being able to do the same activities, have the same friends and hold down the same job, anything else was not considered a full recovery.

> *"And so I'm saying, if it's a mental health thing now, and you know you're capable and your ability, you can do this, that, so many different things in a day, then all of a sudden you have a mental health issue, when you've recovered, you'll be able to do those things again the same as you did before"* [SLaM FG 2, male]

Often for individuals who saw recovery as returning to the same person, this meant no longer needing medication. Individuals noted that they were able to function day-to-day, but they did not consider themselves fully recovered until they were able to do these things without medication or support.

> *"I just think because once upon a time, I used to live a life without medication, why can't I go back to that same thing, after a period of treatment? Do you see what I mean? So my views are very sort of defined; once I wasn't on medication, then I became sick, I took the medication as prescribed, now I'm better, that's how I see it."* [2gether FG, female]

Linked to no longer needing medication was the idea that recovery meant no longer experiencing symptoms, particularly very distressing symptoms such as hearing voices or visual hallucinations. For others, symptoms were not the main focus of their recovery. Instead, being able to function and do 'normal' things again was important to the person, especially where individuals felt that their work, occupations and interests defined their identity. Participants also talked about being able to enjoy these activities. Recovery was seen

as more than just coping and getting through day-to-day life, instead it included taking pleasure in life and "*getting back into life again*" [Interview 6, male].

> *"Well recovery means getting back to normal, my usual self you know getting up in the morning, dressed up go to work, do the job, come home, eat, drink, socialise, take an active part. "* [Interview 7, male]

Category 3.2: Recovery is about change

For some individuals, recovery was seen as moving forward and becoming a new person incorporating new talents, abilities and interests. Part of this process involved leaving the *"old self"* [SLaM FG2, female] behind and gaining a new positive sense of identity.

> *"So I think recovery, what you were saying is that you're not going back to the old you, it's another reality that you're going to. I think when you accept that then you can recover. Because a lot of what's stopping you from recovering is when you can't as you're so far away from who you were. So when you let go of the old person and say 'There's going to be a new one, a better one' hopefully then you'll go quicker towards recovery. That's what I discovered.* [SLaM FG2, male]

One participant in particular, described how recovery was on a continuum with development, where it was no longer about returning to the same as before, but using your experience to develop as a person.

> *"To me recovery is like convalescing, you get out of hospital and you don't feel so well, then in a few months or years you feel much better. By then you feel yourself and that's the beginning of recovery. Then after recovery comes development. Maybe you feel like you're developing new talents and that's development. ".* [SLaM FG1, male]

When asked, the majority of individuals said they would not change having a mental health problem. Instead many people described how they have come to know themselves and other people better through their experiences, and felt that their experiences made them the person they were today.

> *"Would my life be any fuller? I think my life is a lot fuller now. So no I wouldn't change anything to be honest with you. I think I've learnt a lot more about myself and my mental health status in certain aspects and learn more out of it. So yeah, no I wouldn't change at all"* [interview 8, female]

The two categories, “Returning to the same as before” and “Becoming a new person” were not mutually exclusive, but were instead on a continuum. For some people, there were certain areas where they wanted to return to the same as before, whereas in other parts of their life, not only was there an acceptance that things would be different, there was also a desire for the development of new talents, skills and perspectives. For others, although once wanting to return to the same as before, particularly during the earlier stages of the illness, there was now a realisation that maybe this wouldn’t happen. Instead recovery was about becoming a new person, living with the illness and moving forward in life.

> *"You won't necessarily be able to do the things you used to do before, but that doesn’t mean that you’re in a wreck. But if you can manage to cope with the new, then I think you’re fully recovered. I mean, to use an example of an athlete, if that athlete got a little bit older, you wouldn’t expect to them to be able to do the things that they would do as a young fresh athlete"* [SLaM FG2, male]

Category 3.3: Meaning of recovery depends on the meaning of the illness experience

The meaning of recovery was to a certain extent dependent on the meaning the person attached to their experience, or illness. People varied in the explanatory models they used to understand their experiences. In some cases, an individual's explanatory model was different to those offered within services. For example, some individuals talked about their mental health as an eruption or period of extreme stress.

> *"Yeah, I think it was for me personally, a lot of it has to do with stress. If you’re extremely stressed out it’s just one problem piling on top of another, on top of another and you sort of feel trapped and you feel there is no way out"* [2gether FG, female]

Others did not see or *"refused to acknowledge"* their experiences as mental health problems, but instead attended to the physical health concerns and symptoms they experienced. In these cases, people often disagreed with the need for psychiatric care, particularly hospitalisation and medication.

> *"The first time I was in hospital, I knew I was very ill but I refused to acknowledge it was a mental illness, I knew I was physically ill I thought to myself well if it means I can overcome this physical illness I'll go along with it."* [Interview 13, male]

Many individuals described their experiences and behaviours as culturally consistent ways of reacting to negative events. These negative experiences included social problems such as poor housing, lack of opportunity and employment as well as grief and trauma. Racism and

discrimination were also seen as contributory factors, both in terms of being misdiagnosed, and in terms of contributing to a breakdown through stress and prolonged negative experiences.

> *"I was presenting with issues which are cultural and they took them as illness. Culturally we are a loud culture, especially when we are hurt or grieving, we cry and we scream and that is cultural. Doesn't mean you're ill or you're going crazy.... ".* [Leicester FG, female]

> *"A lot of people have experienced very severe forms of racism and somehow it's done something to their psyche, you know?"* [SLaM FG 2, female]

In contrast other people described their experience as an illness and understood it in biomedical terms. This included likening their experience to a common cold or injury. In one case, mental illness was described as a natural occurrence, or something that is *"in your blood"* [Interview 3, female]. For individuals who likened mental illness to physical health problems, or saw mental illness as a biomedical occurrence, recovery was the absence of symptoms and no longer needing medication.

Finally some individuals saw their experience as spiritual or as a form of black magic and voodoo. In these cases, recovery often had a spiritual meaning, and was seen as a spiritual journey out of their control.

> *"My belief is what's happening to me is black magic. Somebody has gone and done something somewhere to affect me in a way. Maybe somebody's jealous or somebody hates me and they've gone to a either a clairvoyant or someone".* [2gether FG, female]

Particularly when religious, these experiences could become an important part of the person's identity and sense of self as a religious person. In such cases, the experience was seen as positive.

> *"The first sign of hearing voices or schizophrenia is that you're wanted by God, a sign that you're wanted by God. And it confirms you to stop doing your bad ways and turn to the path."* [SLaM FG1, male]

Regardless of the meaning of the experience, participants needed to have their explanatory models listened to and taken into account with regards to their treatment. Individuals valued staff who took their beliefs seriously and respected their personal values.

"Well, my carer [name removed], she believes everything I tell her, I tell her sometimes about my prayers and she listened to me. She didn't make fun of me at all, she said to me keep on praying because praying makes you feel contented." [2gether focus group, female participant]

5.3.5 Category 4: Mental health System level facilitators of re/gaining a positive sense of self

The next section of the framework focuses on how individuals can be helped to move from a negative identity to gaining a positive sense of self. For most individuals this transition represented recovery. In general, people recognised the ways in which mental health services could and did facilitate their recovery.

"*One of the things I noticed is that it's good to have a care coordinator, because they can help you to move forward in life, and they help you look more into your illness and why it happened, for example if you have anxieties, to help you with it".* [Leicester FG, male]

Part of the recovery process often involved contact with supportive staff and services which valued identity, uniqueness and personal experience. These mental health system level supports were captured in three subordinate categories: "Being treated as an individual", "Support from the right services and professionals" and "Staff as a facilitator of a positive identity". A large number of themes were included in each of these sub-categories, with participants giving rich descriptions about the ways in which staff and mental health services could support their recovery.

Category 4.1: Being treated as an individual

Individuals did not want to be seen as a diagnosis or label, nor did they want to be viewed only in relation to their race, culture and ethnicity. Instead, people expressed a strong desire to be treated as an individual with their unique experiences, values and beliefs valued by staff. This facilitator of a positive identity was directly linked to staff assumptions. As discussed earlier, staff assumptions were seen as negative with participants describing incidences where staff made assumptions about an individual's care.

"I mean some people might say to me 'Alright you've got an African name or whatever. I'm gonna give you an African therapist" but I was born and brought up in this country. So someone who was born and brought up in Lagos, I've got nothing

against them, but they would not understand my experience, nobody can actually presume what's gonna work for you." [SLaM FG 1, male]

Finding out about the person's background, their unique experiences and individual beliefs as well as their cultural heritage all promoted the sense that services saw them as a person, instead of just a number or label. Staff who focused on their beliefs, values and preferences tended to be the ones mentioned as facilitators of recovery. Specifically in terms of race, culture and ethnicity, this meant staff looking beyond these characteristics and focusing on the whole person.

"*She hasn't looked at me at the colour of my skin or my culture or background; she's just taking me as an individual*" [2gether FG, female]

However, this wasn't the same as ignoring issues of race, culture and ethnicity or avoiding discussions of sensitive issues such as racism or discrimination. Instead staff who promoted a positive sense of identity were able to have these conversations, but on the service user's terms. Individuals wanted to decide what they did and did not discuss with staff, including their previous experiences in services and experiences of racism and discrimination.

"Yeah, understanding, commonsense, and being treated like a human being. Sometimes it's the way you speak to somebody just a simple thing like that. Including people in things, helping them plan. I mean everyone has got different needs so it's hard to speak for everybody". [Interview 12, male]

Category 4.2: Support from the right services and professionals

Recovery and a positive sense of identity could be facilitated by access to the right services and staff. In some cases this included ethnic matching between staff and service users, or having access to a range of services such as talking therapies and peer support. A person's previous experience within services often influenced their choice. For instance, negative experiences with clinicians had an impact on the subsequent interventions and support individuals wanted. One participant described wanting a black therapist as her trust in white therapists, and white people in general, had been damaged by previous negative encounters within mental health services.

"I would like a black therapist; the longer I am in the system the more I fear interaction with white people. Because I've had quite oppressive white therapists and things in my life and like the last woman, she wasn't listening to me. She was judging me and

talking down to me. My only positive experience was with a black woman. I don't think before I went in the system I thought like that." [SLaM FG 1, female]

However, attempts to match individuals to staff members were not always successful. Decisions about matching staff were often simplistic and in some cases used race as a proxy for ethnicity. Black staff were often matched with black individuals, regardless of the person's background, country of birth, ethnicity and their own personal experience.

"It needs to be different for individuals because they are individuals first and foremost whether they are the same colour or not. It is a very thin dangerous line because you might assume everybody from that ethnic group needs the same treatment and you would be wrong. Nowadays you might get somebody who is black but they've grown up in England and their parents have grown up in England, so that'll be different from a black person who has come from the Caribbean or Africa." [Interview 12, male]

Individuals felt it should be up to them to decide which type of service they wanted, and specifically whether they wanted to attend BME or mixed services. One participant further suggested that services should be made more specific to different ethnic groups.

"We shouldn't be forced to mix because I'm black you know? I'm African, I'm not West Indian? And we have a lot of problems between us, so I don't think we should be forced to go to the same centres and all crap things like that. It does work like that, because even the Irish come into BME and Scottish come into BME, you know? So they are recognised, so Africans should be recognised as well as West Indians, you know? We're different." [Interview 2, female]

However this wasn't necessarily a view shared by all participants. In contrast, some individuals felt there shouldn't be BME specific services, and that instead, individuals should mix with all services users regardless of race, culture and ethnicity.

"Everybody should get along with each other, people shouldn't discriminate. They should just be there for them, everybody should get on well... You have certain, service users that use different services for people with different backgrounds which is wrong. Everybody should be together as one." [Interview 1, female]

When it came to discussing the types of services and interventions wanted, access to talking therapies was particularly important. Many individuals felt they were denied this option, and

were instead given medication as the only alternative. People felt that there was a particular problem with black individuals being offered talking therapies.

> *"One of the problems a lot of black people are complaining about is that they're not given talking therapies. You know, I've seen black people walking on the street, where I feel like crying because they're totally vulnerable on medication swaying from side to side"* [Interview 9, male]

In essence, people wanted choice about the services and treatments they received, the staff members they saw, the places they accessed and the activities they undertook. What was considered *"the right services"* [Interview 6, male] including whether people attended a BME service or not, differed from person to person. It was important to find out about the individuals values and how this impacted on their treatment preferences when helping people to plan and access supportive services.

> *"I think the support and services should be on a choice basis. rather than staff assuming 'we know what we need, you need medication, you need activities, you need this, you need that' Instead of presuming you know what somebody needs in that sort of situation"* [Interview 12, male]

Category 4.3: Staff as a facilitator of a positive identity

Working relationships between staff and service users were important facilitators of recovery and in some cases determined whether people felt good about themselves. Staff needed to treat people as individuals, avoid making assumptions, have time for the person and believe the person's story. There were certain qualities of staff, such as being a good listener, trustworthiness, openness and honesty that helped the service user to feel valued. Within a recovery-supporting relationship, these skills were used by staff to help individuals feel involved in their care and to feel more empowered.

> *"Having staff that enable you to have an input into what services you get, what kind of therapies and treatments you get, you know? Being able to chat with the nurse, the doctor, the psychiatrist, is not always telling you what they think is good for you, but you also being able to input into it. All that, being empowered, all that are stages of recovery."* [Interview 2, female]

The issue of personal characteristics of staff members, such as their race, culture and ethnicity was an important topic, and one which divided opinion. For some individuals it was very important to have a therapist or staff member who shared the same race, culture and

ethnicity. This was particularly important during times of crisis, where having staff who could speak the same language, or who shared the same cultural references made the process easier.

> *“I remember there was a South African nurse, she was really helpful, because she identified my problems because when I was not well I was singing a lot, being an African she knew that it's another way of releasing that stress, and she managed to get in touch with my family back in Zimbabwe…. She helped me because I think she made the consultant aware of my background.* [Interview 14, TEWV, female].

In some cases however, having someone from the same culture or ethnicity could be a barrier to recovery. This was true where the person experienced greater stigma from members of their cultural or ethnic group.

> *"Yeah well, when it comes to me though, anyone who’s come to help me I always accept them and make the best use of it. But if I had the choice, I would avoid seeing an African psychiatrist..... The reason being, Africans, they have certain views about mental illness. Now an African family would never admit that they’ve got a son or daughter with mental illness. They will hide it."* [Interview 7, male]

For many individuals, the personal qualities of the staff member were more important than their ethnicity and background. Other factors and characteristics such as gender or age could be more important. For these individuals, the cultural competence of staff was more important than the person's culture or ethnicity.

> *"I think it would be wise if staff learned about these things and had them as tools brought out when needed but not just assuming that I am going to need this tool today because I’m dealing with a Chinese man or a black man or whatever. But it would be nice if they knew about these things but not necessarily assume that when you see somebody of that colour they'll need it"* [Interview 12, male]

Regardless of their views on ethnic-matching, individuals discussed how race, culture and ethnicity were not the only important factors in the working relationship. Just because an individual was matched on ethnicity or certain elements of their culture, did not guarantee they would get on. Many individuals described how, as with any other relationship, sometimes it just did or did not work.

> *"It’s not the colour of them, it’s not the sex of them, it’s just when you meet them if it clicks and then it clicks next time.* [SLaM FG 1, male]

5.3.6 Category 5: Facilitators of a positive sense of self beyond the mental health system

Although for many people staff and services could support an individual's recovery, many of the facilitators towards regaining a positive sense of identity were outside mental health services. This was captured in the final category. As with "Defining the self", the facilitators beyond the mental health system can be seen as part of a socio-ecological framework.

Category 5.1: Individual / intrapersonal level facilitators of a positive identity

Individuals came up with different ways that they were able to boost their own self-esteem and work towards their recovery. People mentioned the importance of *"learning to live well again"*, and *"cope with the negative".* In many cases, this meant living with the illness and/or experience or learning to move beyond it, with or without support.

> *"You can have as much support as you want but it needs to come from yourself, because lots of people have got lots of support but they might still relapse or they might still get unwell. So it is something you have got to recognise within yourself. And I think support is exactly what it is. It's support. But the main thing has got to be done by the individual.* [Interview 12, male]

People had many practical ways they could learn to cope and live with the illness which ranged from *"eating well*" to *"finding time for myself"*. One way of coping with the illness common amongst participants was to build up daily routines, and have a sense of stability. For some, this was the start of recovery, and could involve new skills and hobbies. Once the person felt settled and secure they could work on personal growth and developing as a person.

> *"I mean, at the time, I was trying to learn to live again, you know, the basics like to eat and walk and talk and cook yourself a meal or something.* [2gether FG, female]

Part of managing your day-to-day life included being able to recognise the signs and symptoms of becoming unwell. This also included accessing help when it was needed and having plans to deal with times where the person was unwell.

> *"They need to address a couple of things. Because if everyone's who's been to hospital once or twice has a little bit of experience to say 'You know what? I know what makes me worse; I know what makes me better'. They should be encouraged by their CPNs, 'Alright, write an advanced directive so that if you become unwell, this is what you would like to happen'."* [SLaM FG 2, male]

For some people having a greater understanding of their illness made recognising the signs and symptoms of relapse easier, and ultimately made them feel more in control of their lives. This included recognising the stressors and experiences that made them feel unwell, and actively working to avoid these situations wherever possible.

> *"For example when I was doing my studies, when I feel like I am not well, I'd leave it for some time and when I feel that I am much better I start to continue with my work and it actually helped me because if I wasn't doing that maybe I could have my relapse."* [Interview 14, female]

On top of understanding and managing their mental health experiences, physical health and appearance were just as important. People mentioned strategies for staying well physically, including exercising and eating healthily. Many individuals felt that having a healthy body was good for their mental health, with one participant stating "*healthy body, healthy mind*". Looking after your physical appearance was also a way of boosting your self-esteem, especially when in hospital when individuals felt their individuality had been compromised.

> *"I think beauty also helps, for females anyway. The way you present yourself. When I was in hospital, I couldn't do my hair, I couldn't put a weave, it wasn't nice and neat or anything like that, it was just left messy. I was wearing the same clothes and I smelt. No matter how sick you are, every female has to shower, you have to change your clothes..... One good point I must highlight about [name of hospital removed] is that they had a beauty bar where they fixed your nails and they did your hair and that made me feel good."* [2gether FG, female]

In addition to coping with their mental and physical health on a day-to-day basis, individuals also mentioned the importance of having plans for the future. This gave people a sense of hope and optimism People took great pride in their determination to "strive" forward in life and their ambition to succeed. It was also important to have a positive outlook towards life.

> *"You've got to look out for yourself and look forward, and look for the positive and be positive and if you look positive and be positive things will be positive and you will get your goal, you will go forward"* [Interview 6, male]

Category 5.2 Connecting with people - interpersonal facilitators of a positive identity

For some people, the collectivist identity was a prominent feature of the self and included being connected with other people both interpersonally and within the wider community.

People saw themselves in terms of their social roles and responsibilities. "Connecting with people - interpersonal level" and "Community and social level" capture the collectivist elements of individual's identity.

Many individuals described feeling an overwhelming sense of isolation. Part of regaining a positive sense of self was to overcome this isolation. This included catching up with friends and family, and being part of society once more.

> *"I wasn't close with them. I used to push them away as well. But now I don't push anybody away, I talk to people now. I've got more close friends now. People are there for me if ever I need them. To have people and the service there for you if you need them."* [Interview 1, female participant]

Recovery often included the whole family. Participants often described how they were getting well for their whole families as well as themselves. This not only acted as a support to the individual, it was a source of motivation, particularly where individuals had a unique and important role within the family.

> *"I don't get well for myself, I get well for my people, they know that everybody is happy. They know I can play a certain part in the family which nobody else can do, it has really helped me".* [Interview 8, female]

For other individuals, although connections with supportive family, friends, professionals and peers were important, people ultimately saw recovery as being able to move on from needing this support. In these cases people wanted to independently live their daily lives without the need for support. For some, this linked to more individualistic goals of recovery, where independence and self-reliance are seen as the primary aims.

> *"So sort of being able to accomplish daily tasks, I think this is what I believe wellness is, being able to accomplish daily tasks without that extra help or without the help of medication, being able to get up in the morning and go to if it's a nine to five job, you've got to go to a nine to five job"* [Gloucester FG, female].

Category 5.3 Community and societal level facilitators of positive identity

The final theme including in this category related to the wider elements of society, including community membership. Connections at this wider level could also include connections with nature and spiritual connections. In many cases, community membership was an important facilitator of recovery with people talking about their desire to give back to their communities.

Individuals felt it was appropriate to be treated in the community and to use the natural supports available to the person instead of relying on mental health services.

For individuals who had experienced an identity crisis, the community gave people a sense of belonging and helped to minimise any experiences of *"otherness"*. For some, the very definition of recovery involved getting back into the community.

> *"Yeah, to go back to the community and do what things which you would have done besides, without taking into consideration the illness, I think that's what recovery means to me.* [Interview 14, female]

Belonging to a collectivist culture, sharing cultural values and history with other people could also be a source of pride. This included wanting to find out more about their cultural heritage and to visit different countries important to their background, particularly at times where the individual felt threatened by their experiences within the UK.

> *"I have points when I'm like 'oh I just want to go to Africa and live' and I, and my parents, wasn't even born in Africa, so, why would I be going to Africa?, But because I know like my history, that black people come from Africa it's like I'm thinking that would solve my problems"* [Interview 10, female].

Religion and faith communities could also give people a sense of belonging and a positive identity. Some individuals defined their identity in terms of their religion such as *"I'm a Christian"* [Interview 1, female] or *"I'm a Muslim"* [Leicester FG, male]. Religion and spirituality were also seen as important sources of strength and resources to call upon, especially during difficult times.

> *"I depend on as well my religion because I'm a Muslim. When I pray and open my heart to God, I feel great comfort come to me. So this helped me with the recovery mentally. I feel when I pray that I am stronger"* [2gether FG, female]

However, identifying with a collectivist self could have a negative side. Belonging to a collectivist culture could introduce a greater level of stigma and discrimination, especially where mental illness was regarded as a weakness within the wider community. Being accepted by another community could help people to feel wanted, particularly where community membership did not depend on the colour of your skin, your background or cultural heritage

"It was a bit difficult to get back to the community especially with those who saw me when I wasn't well, it was quite difficult to re-engage myself with my friends, as most of them they were from Africa. It was quite difficult as once you've that problem, you're an outcast, they can't take you back. Even if you are well, there's some stigma attached to that illness." [Interview 14, female]

For some individuals, the mental health experience made them feel worthless. Many described feeling like they didn't have a purpose or a contributory role in society. For these individuals, recovery involved not only being an active member of society, but giving back as well. For some this meant paid employment and no longer having to rely on the welfare system, whereas for others it included voluntary work. In particular, individuals felt good when they were able to use their own experiences to help other people going through similar difficulties.

"For me I just like to generally help myself or help others in the same ways that I help myself and things like that and make it into a positive way, And just by helping other people at the same time as enjoying helping people. [Interview 6, male]

5.4 Reflexivity

In line with a subtle realist perspective, it is important to consider the impact that I may have had on the data collection and analysis process. Within the interviews and focus groups my own ethnicity may have influenced the topics discussed. A distinction has been made between different types of self-disclosure, including unintentional/automatic self-disclosure [240]. In this case, race and ethnicity were important concepts explored within the interviews. As a white female researcher, I was mindful of the impact that this unintentional self-disclosure may have on the participants and especially on the power relations between me and the participant. Throughout the interviews I was mindful of any potential power dynamics, especially when discussing sensitive issues around race, culture and ethnicity. These impressions were recorded as memos following data collection and re-visited during the analysis.

To ensure that the questions and prompts used in the study were culturally appropriate, the topic guides for both the interviews and focus groups were developed in consultation with the BME virtual consultation panel. However, despite this approach, it was still possible that participants may not have felt comfortable discussing issues around race and racism with a

white researcher. One way of overcoming this issue was recommended by the BME virtual consultation panel, who suggested that participants may need explicit permission to talk about race and racial discrimination. This was achieved in two ways. Firstly, through the use of open but explicit questioning, and then secondly through the use of previous quotes from earlier focus groups, where race, ethnicity and culture were openly discussed. The aim of these approaches was to enable the interviewee to feel comfortable and confident in discussing difficult and potentially upsetting areas.

It is important to note however that reducing ethnicity down to purely skin colour also simplifies the complex and nuanced nature of an individual's identity. For instance, although black in racial terms, someone from Africa may not share much in common, (other than the notion of otherness in a white society) to someone from the Caribbean. As ethnicity is a multifaceted and dynamic concept, the approach taken in the interviews was to get to know the people taking part. This meant finding out about the person and what was important to them. Part of getting to know the individuals involved letting the participants get to know me. For example, during the recruitment period I spent a lot of time at two voluntary sector day centres and BME groups. If individuals asked questions, including why I was interested in this area, I tried to be as open and honest as possible, and would disclosure information to help the individuals feel more confident and comfortable with me. For example, I frequently discussed being in a mixed-race relationship.

During my time getting to know the individuals, one participant even stated *"you're the blackest white person I ever met"*. This was after using dominoes to start up a conversation about the research process. In this case, I was invited to play a game with an individual, it was only after winning the game that the person asked what I was doing at the club and then proceeded to ask to be part of the study.

Finally, where individuals were not comfortable discussing sensitive issues with a white interviewer, they were given the option of having an interviewer from a black background. This involved training and working in collaborating with members of staff from a BME day service. This enabled me to include a participant who had approached a staff member about taking part in the research but who did not feel comfortable being interviewed by a white researcher.

In addition to the process of conducting the interview, I was also mindful that my own experiences may have influenced the data interpretation. My own ethnicity may have meant that I paid more attention to some themes in the transcripts and 'down-played' those themes which may have been potentially challenging to my own sense of identity. Alternatively I may have been more sensitive to these themes. Reflexive notes and memos were kept throughout the data collection and analysis phases to record thoughts and assumptions that may have influenced my interpretation of the data.

5.5 Discussion

5.5.1 Main findings

This is the first qualitative study to explore the perceptions of recovery and recovery support for black individuals who are currently using community mental health services. The core category from the analysis related to identity and (re)gaining a positive sense of self. In particular, the process of recovery involved moving from a negative sense of identity to a more positive sense of self. Many factors contributed to a negative sense of self. These were divided into societal threats and threats posed by the mental illness experience. Societal threats related to how the individual felt as a black person within a predominantly white society and included experiences of racism or discrimination. The threats posed by the mental illness experience included not only the potentially damaging impact of having a mental health problem on the person's sense of integrity, but also included the impact of previous negative experiences within mental health services. Mental health services were associated with a loss of identity and with the person feeling they were no longer seen as an individual. This was coupled with the societal threats, including those associated with race, culture and ethnicity, which meant individuals often felt that they belonged to multiple stigmatised groups.

People needed to move from this negative sense of self in order to feel recovered or in the process of recovery. For some people this involved becoming a new person with new skills, talents and interests, whereas for others, recovery was a return to the same person as before. This difference in returning to the same or becoming a new person could be viewed as a continuum, with many individuals wanting some aspects of their identity to return to the same as before, whilst wanting to develop in other areas. Many facilitators of recovery could help people regain this positive sense of self.

Individuals described the different ways in which mental health services could help them feel more positive about their sense of self, and hence aid recovery, this was of particular importance to the remainder of the thesis. The mental health level facilitators included having staff members who valued and respected the person as an individual with a unique story and background. Individuals also expressed a desire to access a range of services and professionals. What was considered the right service for one person however, may not be right for another. Rather than a "one size fits all approach" the individual's treatment preferences were linked to their values. In essence, one way staff could aid recovery and the promotion of a positive self-image was by gaining an understanding of the person's values and treatments preferences.

These findings can be summarised in a Framework of Recovery Support. The Framework is presented schematically in Figure 5.1. The Framework of Recovery Support directly influenced the development of the pro-recovery intervention, and in particular helped with the identification of underlying recovery principles for black individuals.

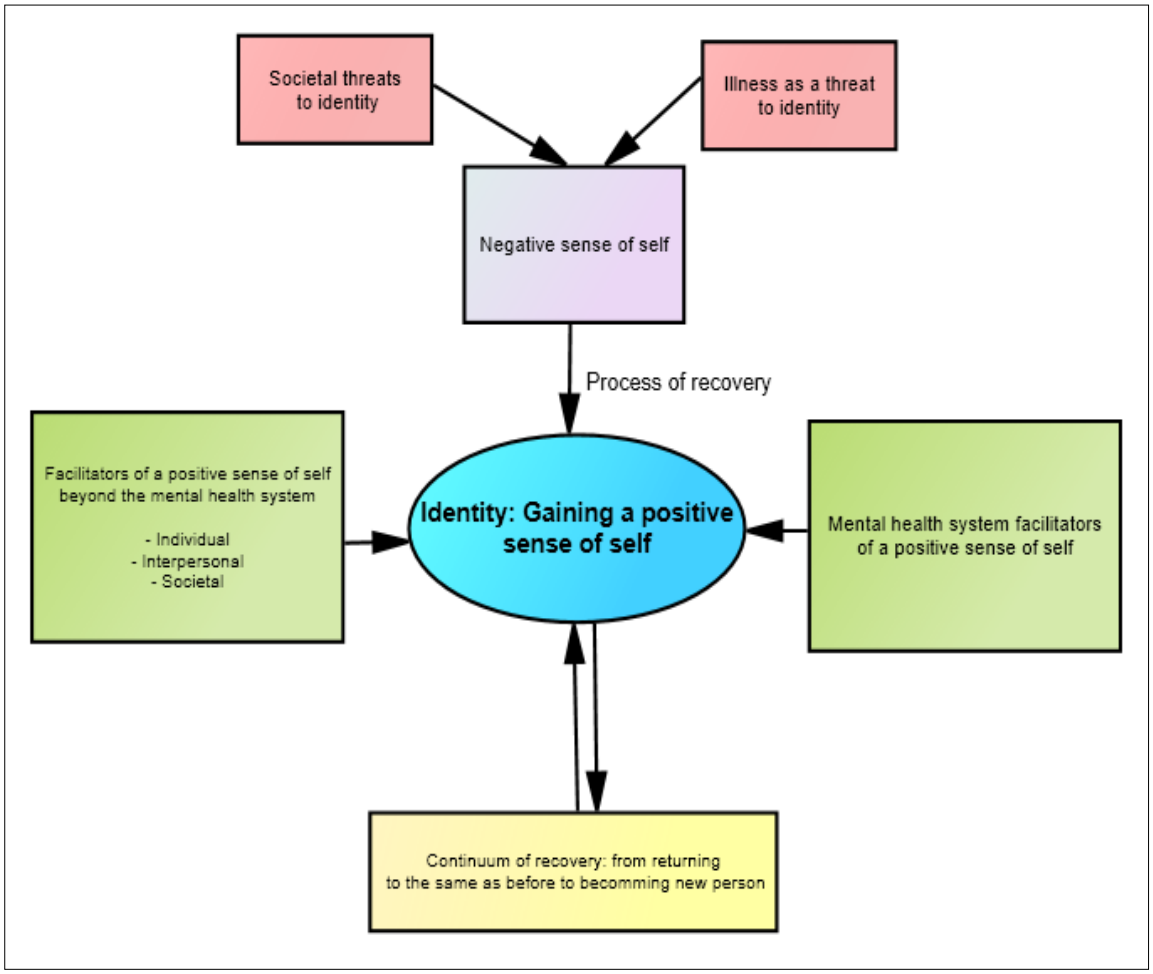


Figure 5.1: The Framework of Recovery Support

5.5.2 Strengths and limitations

The qualitative study had five main strengths.

Firstly, this is the first qualitative exploration of the perception of recovery for black individuals who use community mental health services. The study also assessed what types of supports and relationships individuals felt could support their recovery both within and outside mental health services. This study helps to overcome the knowledge gap previously identified in Section 3.4.5 relating to the lack of previously published research assessing the meaning of recovery for black individuals. Furthermore, the study aimed to address the '*monocultural*' nature of recovery research [28].

A second strength was the methodological rigour of the study. This included the explicit epistemological basis. The study also included a convenience sample with a purposive sampling frame employed to ensure individuals were recruited across voluntary and statutory sectors with particular attention paid to the composition of the group. This included sampling individuals from statutory and voluntary sector organisations, ensuring individuals were recruited from different mental health team types (e.g. early intervention, forensic, support and recovery) and that individuals varied in the length of time they had used services. Finally, a rigorous thematic analysis which made use of techniques from grounded theory including constant comparison [238] was used for the analysis.

A third strength was the use of methodological and participant triangulation to increase the breadth, depth, relevance and validity of the findings. Two methods of data collection were used in the study. Focus groups aimed to elicit the group perspective, whilst interviews focused on the in-depth individual experience. Within focus groups, the researchers are in a less commanding position, with the group, to a certain extent controlling the topics of conversation. This contrasts with the individual interviews where a more focused and in-depth discussion can occur. Participant triangulation was achieved through inviting individuals from the focus groups to attend individual interviews. This allowed for the further discussion of any emergent themes from the focus groups, and for the researcher to test the interpretation of the data. Individuals were also asked to take part in an interview if they did not agree with the group perspective voiced within the focus groups. This allowed for the in-depth exploration of deviant cases which added to the richness of the data.

The fourth strength relates to the culturally sensitive manner in which the focus groups and interviews were conducted. Halcomb and colleagues argue that ultimately the success or failure of a focus group depends upon the cultural sensitivity of the research team [241]. I was mindful of cultural sensitivity throughout. For instance, one of the groups was held during Ramadan, in this case the lunch usually provided to individuals was not placed in the same room as the focus group and individuals who were Muslim were invited to take food away with them. Furthermore, we sought to provide a range of different foods for individuals, including Halal food. The reflexivity section further outlines the approaches taken to ensure a high level of cultural sensitivity (see section 5.4).

The final strength of the study was in the use of the BME virtual consultation panel to provide guidance on the development of the topic guides. The BME virtual consultation panel suggested adding explicit references to racism and discrimination within the topic guides to give people permission to discuss these sensitive topics. This was consistent with the experience of mental health services, where individuals within the study discussed how they wished to have conversations around race, culture and ethnicity, including the impact of racism.

Four limitations of the qualitative study can be identified.

Firstly, one limitation was in the inclusion of individuals from other BME backgrounds within two of the focus groups. The decision to include individuals from other minority ethnic backgrounds was pragmatic and based on the number of eligible individuals able to take part in the focus groups. Morgan recommends that focus groups should include between four and eight participants to ensure that a group dynamic is achieved [234]. In some Trusts, the number of eligible individuals who self-ascribed their ethnicity as black was not sufficient to allow for the recruitment of four to eight individuals. Consequently, recruitment in these areas was opened up to individuals from other non-white minority backgrounds. Although the experiences varied, all participants shared in common the experience of being in a non-white minority group within UK mental health services. Halcomb and colleagues argue that group composition, and in particular achieving a homogenous group is crucial to the success of a focus group [241]. Recruiting individuals from a range of backgrounds may have reduced this homogeneity. However, within focus groups which were restricted to individuals who self-ascribed their ethnicity as black, groups were heterogeneous as the term black represents a very heterogeneous group with many different ethnicities and cultures.

A second limitation relates to the impact that being a white researcher interviewing black individuals may have had on the results of the study. This limitation is common throughout the thesis. Throughout the study attempts were made to minimise the impact of being a white researcher, whilst also ensuring that I remained mindful and reflexive throughout the process. A number of approaches were taken to minimise or reduce the impact of the researcher-participant dynamic. These were discussed in Section 5.4 and included giving participants the choice of being interviewed by a black researcher, the thesis author receiving training in qualitative interviewing delivered by individuals from BME backgrounds, getting to know people prior to the interviews and having an open approach to disclosing my own ethnicity and personal experiences.

A third limitation common to the majority of research studies is that the participants were self-selecting and may not be representative of the population who use services. In particular, participants within the study may represent extremes in opinions, e.g. those very satisfied or dissatisfied with services. The sampling frame aimed to overcome this limitation by recruiting a range of individuals including those who used voluntary and statutory sector services. Furthermore, the use of deviant case analysis and participant triangulation, aimed to reduce the impact of extremes in opinions.

A final limitation of the study was that only participants who could speak and understand English were included. It was beyond the scope and resources available to the thesis to provide translators. Future research could overcome this limitation by conducting interviews and focus groups with people from black communities where English is not their first language.

5.5.3 Links to existing literature

Many of the themes included in the Framework of Recovery Support were common to the Conceptual Framework of Personal Recovery. It is important when discussing the findings of this study, and of the thesis in general, not to overstate the differences between majority and non-majority populations but instead to acknowledge the many similarities common to individuals regardless of their ethnicity. The aim of the study was to investigate the experience of recovery for black people and not the difference in experience between black and white individuals. Consequently, many of the themes are not specific to black individuals.

With this consideration in mind, the results of the present study are now discussed with reference to the literature.

The perceptions of wellness for BME individuals at risk of developing psychosis has been explored using q-type methodology and qualitative interviews [164]. Perceptions of wellness were associated with cultural beliefs, such as viewing the self in a social sense, and the importance of family and community. Consistent with the present study, individuals described contributing and giving back to the community as a sign of wellness. Finally, one area common to both studies was the importance of having professionals and mental health staff who understood the person's cultural, religious and spiritual background including their values and beliefs. Having understanding mental health staff was more important than the ethnicity of the staff member.

Identity was the core category within the analysis of the present study, with regaining a positive sense of self, central to the recovery of black individuals. Previous research, although not specifically focused on individuals from minority backgrounds, has also highlighted the importance of identity within recovery. Wisdom and colleagues explored identity-related themes in the personal accounts of recovery from the perspective of people with lived experience [242]. Forty-five personal accounts within the literature were analysed with five main identity-related themes included in the analysis. Consistent with the present study, individuals described a loss of sense of self, such that mental illness was seen as taking away aspects of the person's identity [242]. A review into the use of metaphors in the accounts of people with lived experience of psychotic disorders similarly found that many of the metaphors described this loss of self [243].

In the present study, part of the recovery process involved a transformation into a more positive identity. Participants were on a continuum of recovery from returning to the same as before to becoming a new person. The continuum between returning the same and becoming a new person echoes the distinction made between 'recovery from' and 'recovery in' [114]. Davidson and Roe distinguish between symptom amelioration and returning to the same as before the illness (recovery from) and living a hopeful and satisfying life including personal growth resulting from the experience of mental illness (recovery in) [114]. For participants in the present study, there was not a fine line between recovery from and recovery in mental illness; both can be important to the person. Moreover individuals in the present study described areas of their lives where symptom amelioration and returning to the same as

before were important, whilst also acknowledging the need and desire to grow and develop in other areas.

A number of identity theories exist within the literature, and although a comprehensive review of the different theories is beyond the scope of this thesis, the results of the present study can be viewed with reference to the social identity approach [244,245]. The social identity approach consolidates the earlier social identity and self-categorisation theories, and was originally developed to explain intergroup relationships, including stigma and discrimination [246]. According to the social identity approach, identity is constructed and defined along a continuum from personal identity to social identity. Within this context, personal identity refers to the person's unique characteristics, such as their personal attributes, likes, dislikes, strengths and abilities which differentiate them from similar others. In contrast, social identity is made up of the characteristics of the group(s) which the individual identifies with. These group characteristics are shared between individuals and differentiate that group from other dissimilar groups [244,245,246].

Within the social identity approach, shared group characteristics are influential in structuring the individual's self-concept and are used by individuals to define their sense of self. Furthermore, group membership provides support and guidance as well as a framework for understanding the social world [246,247]. The personal and social elements of the self are used to make social comparisons, particularly between groups. According to the approach, such group comparisons underlie group dynamics, including stigma and discrimination [248].

In line with a social identity approach, individuals in the present study frequently made comparisons between themselves and others including both upward and downward comparisons. Social comparisons allow an individual to establish a benchmark they can use for evaluating the self. Downwards comparisons, whereby the individual compares her/himself to an individual in a worse social situation, served to not only normalise the previous distressing experiences of a person, but also increased the individual's self-esteem. In particular, downward comparisons were made to individuals who were in hospital, and upward comparisons were used as benchmarks to indicate when the person felt they would be fully recovered [247,248].

Social identity theories also help explain the impact that belonging to disadvantaged groups can have on the individuals sense of self [249]. Within the present study, individuals described

the impact of belonging to multiple stigmatised identities. This echoes what has been previously reported in the literature [156]. This questions whether people from already disadvantaged and undervalued groups can consider themselves truly recovered.

In addition to the links with the identity literature, the findings of the present study can also be linked to previous reports discussing the experience of black individuals within mental health services. As discussed in Chapter 2, the Breaking the Circles of Fear report highlighted the existence of a circle of fear in which black individuals and communities were fearful of interactions with mental health services [81]. Within the present study, individuals described the negative experiences of mental health services, including how communities were often fearful or lacked understanding of mental health. Furthermore, helping the community to have a better understanding of mental health problems, and hence to reduce the stigma associated with mental ill health, was seen as one facilitator of recovery.

Another key finding from the Breaking the Circles of Fear report also evident in the present study was the culture of avoidance when it came to discussions around race, culture and ethnicity within mental health services [81]. This avoidance has been termed 'professional paralysis', whereby staff members do not feel they have a safe space to discuss these issues with service users, particularly those from a different background for fear of being branded a racist or discriminatory. This was echoed in the findings from the focus groups where some participants talked about wanting an open dialogue to discuss issues concerning race, including the experience of racism. What was important for participants was that this was done on an individual basis. In particular, it should not be assumed that all individuals would or would not like to have these discussions, nor should it be assumed that all individuals had or had not experienced racial discrimination.

5.5.4 Clinical implications

The findings of the present study have four implications for clinical practice.

Firstly, the results indicate that in order to support recovery, there is a need to find out what is important to the person and how this impacts on their treatment. In particular, service users expressed a need for staff to find out about the whole person, instead of just focusing on certain aspects (e.g. illness for example).

The second clinical implication related to the need to reduce staff assumptions about the person. Individuals noted that within services they were often classified and grouped based on racial categories used as a proxy for ethnicity and culture. Fernando notes that services and staff often hold common beliefs linked to racial and ethnic groups which may or may not be applicable to any one individual within a particular group [250]. The main finding within the study referred to the need to treat everyone as individuals and to reduce the assumptions that are made.

The third implication linked to the provision of BME specific services and staff. The results of the study highlighted that not everyone from a BME background wanted a BME service. Instead the desire and need for BME-specific services was more complex, with some individuals wanting them all the time, others not at all, and some people wanting them some days but not others. It was also clear that BME was used as an overarching label. For instance, BME services would cover all individuals from BME backgrounds regardless of the different ethnic groups, who may have very different cultural needs and belief systems. Furthermore, many of the individuals from BME backgrounds were born in the UK. This raised questions about treating all individuals classified as BME within the same service. For instance, the experience, cultural beliefs and upbringing of a black man born and raised in the UK may be very different to the experience of a black man born and raised in Africa and entering the UK as an asylum seeker or refugee. Individuals also varied in their preference for ethnically matched staff. The results suggest that the notion of ethnic matching may be an oversimplification of the complex working relationships between staff and service users, and that the focus on race and ethnicity may negate other areas important to the person.

The final implication is that services should actively engage in attempts to overcome the social isolation of black individuals with mental health problems. In particular, services should take an active role in mental health promotion and education, with the aim of reducing the stigma associated with mental illness, particularly in black communities. In line with this principle, many individuals in the present study discussed their experiences of mental health stigma and discrimination. Many individuals wanted practical solutions, including the provision of mental health education within the wider community.

5.5.5 Implications for future research

There are two main research implications of this study.

As this was the first empirical investigation within this area, there is a need to further validate the Framework of Recovery Support with other black individuals from different locations within the UK. In line with a subtle realism perspective, this would provide evidence of relevance and validity.

A second implication for future research could be to test the Framework with individuals experiencing a first episode of mental illness. The individuals within the present study had used services on average for ten years, and talked about the long-term impact of using mental health services. Future research could assess whether there are differences in what recovery means and the support individuals want based on their stage of illness.

5.5.6 Implications for the thesis

Many of the implications for the thesis directly linked to the clinical implications. Specifically this chapter had three implications, which concerned the design and focus of the pro-recovery intervention developed within the thesis.

Firstly, the chapter provides an overview of the underlying recovery principles for individuals from black backgrounds. These underlying principles regarding the meaning and perception of recovery were used to inform the intervention, model and manual (discussed in Chapter 6).

The second implication related to the intervention content. The study highlighted the need to support staff to get to know the individual. The underlying principles identified in the study included focusing on identity, reducing assumptions, allowing the person to tell their story, focusing on the individual's values and treatment preferences and overcoming the professional paralysis relating to discussions around race culture, ethnicity and racism. The intervention developed as part of this thesis aimed to focus on these areas in order to help individuals develop a positive sense of self.

Finally, during the later individual interviews, participants were asked what types of information they would wish to share with staff. This included the types of conversations or activities they could engage with in order to share their stories and discuss their values and treatment preferences. The themes from this part of the interviews as well as the over-arching themes of being treated as an individual, were used to guide the development of the pro-recovery intervention and will be described in more detail in Chapter 6.

5.5.7 Conclusion

This chapter described the development of the Framework of Recovery Support. The framework highlights how the process of recovery for individuals from black backgrounds involves moving from a negative sense of self to gaining a positive sense of identity. Facilitators of this positive sense of self occur within and beyond the mental health system and can be viewed within a socio-ecological framework.

Chapter 6 Development of the REFOCUS Intervention

6.1 Introduction and aim

The literature review presented in Chapter 4 highlighted a lack of empirically evaluated pro-recovery interventions for black individuals. This provided the rationale for developing a new culturally-sensitive pro-recovery intervention and evaluating the intervention within a cluster RCT. The overall aim of the REFOCUS intervention (as discussed in Section 1.1) was to improve the recovery-orientation of community mental health teams. The intervention adopted a whole team approach, such that it was intended to be delivered to all members of the clinical team, and focused on increasing staff attitudes and values consistent with the principles of recovery. To achieve this aim, a new pro-recovery intervention was developed.

Intervention manuals typically specify the content of an intervention and outline the active ingredients included. There are three main benefits of manualising an intervention. Firstly, an intervention manual can facilitate the implementation and use of an intervention within practice [251]. Secondly, manuals can help standardise the treatment provided by different clinicians and teams, which is an important consideration for most RCTs, particularly trials aiming to explore the impact of different elements of the intervention [252]. Finally, manualising the intervention also enables future replication and generalisation across settings.

Based on the above rationale, a manualised approach was adopted for this thesis. This approach was in line with the MRC framework [31]. However, developing a manualised intervention presents a number of challenges for any pro-recovery intervention. In particular, definitions of personal recovery stress the unique and individual nature of the journey for people [25,110,253]. This created a tension between developing an intervention which was both invariant (to allow it to be evaluated) and individualised (to reflect idiosyncratic differences in recovery). This tension was addressed within the present thesis by the development of an intervention which was rigid in structure but flexible in delivery. This included developing an intervention manual which aimed to provide guidance to clinicians without being too prescriptive.

The aim of this chapter was to develop a section of the REFOCUS Intervention to be tested within the REFOCUS cluster RCT. The objectives were:

Objective 1: To use underlying principles to develop a component of the REFOCUS Intervention.

Objective 2: To develop the REFOCUS Model, which outlines the anticipated effects of the intervention components on staff and service user outcomes.

Objective 3: To describe the intervention and model within the REFOCUS Manual. The REFOCUS Manual was published as part of the Rethink recovery series [254] and is downloadable from researchintorecovery.com.

Underlying theoretical basis

The MRC framework proposes that all complex interventions should have a clear theoretical basis [31]. The goal of the theoretical basis is to specify the active ingredients of the intervention, including the intervention goals and anticipated effects. The theoretical basis of the REFOCUS Intervention involved the identification of underlying recovery principles. The underlying recovery principles guided the content of the intervention, and the way in which it was delivered.

Three sources of data were used to identify the underlying recovery principles. The first source used was the Framework of Recovery Support for black individuals developed in Chapter 5. A key component of the Framework: "Mental health system level facilitators of re/gaining a positive sense of self" was used to guide the intervention. Secondly, the Conceptual Framework or Recovery developed in Chapter 3 was used to ensure that the content of the intervention was aligned with the meaning of recovery for people using mental health services. The third source was the Recovery Orientated Practice Framework, which was developed from a thematic analysis of existing recovery indicators, practice guidelines, competencies and standards [110,255]. The aim of the analysis was to synthesise the best available recommendations for recovery-orientated practice internationally into a coherent framework, within which the intervention could be located.

The underlying principles of the REFOCUS intervention resulting from a synthesis of the three evidence sources described above are shown in Table 6.1.

Table 6.1: Underlying intervention principles

Data source	Underlying Principle	Implication for the REFOCUS intervention
1 and 2	Personal recovery is individual and unique	The intervention needs to be flexible and delivered in an individualised way. The intervention should avoid a 'one size fits all approach'.
1 and 2	Service users value individualised care	The individual's values and treatment preferences are central to a recovery-orientated service. Care planning should be built upon the individual.
1	Identity is a multi-dimensional concept	The intervention needs to focus on multiple areas of the person's identity.
1	Race, culture and ethnicity are only elements of identity.	The intervention should encourage staff to consider all areas of identity important to a person, instead of focusing on just a few areas.
1	A positive sense of identity is important to recovery	Care planning should focus on the individual's values and strengths.
1	Some staff make assumptions based on race, culture and ethnicity. Staff assumptions can impact on identity.	The intervention should support staff to understand the values of each person, to enable staff to get to know the individual better.
1 and 2	Some individuals are sceptical about recovery	The term recovery is only used where an individual finds it helpful. Terms such as "well being" or "living a good life" may be more acceptable to some people.
2&3	An individual's values has an impact on their treatment preferences	The intervention should support staff to understand the treatment preferences of individuals.
2	Recovery is an active process	Recovery is not something simply "done to" the person.
2	Recovery can occur without professional support	Clinical expertise is recognised as a support alongside other types of help which may contribute to an individual's recovery.
2	Practical support, diagnosis and medication are all important.	Recovery and the REFOCUS intervention do not replace current mental health practice but are in addition to routine care.
2	Five domains are important recovery processes	The intervention should aim to target the five CHIME recovery processes.
2	Different support is needed at different stages of recovery	The target group for the intervention are people who are currently using outpatient community mental health services.
3	Recovery spans four domains of practice	The intervention will target two of the practice domains included in the Recovery-Orientated Practice Framework most relevant to front-line staff. These are "Supporting personally defined recovery" and "Working relationships"
3	The processes of care are important to recovery-orientated practice.	The intervention needs to address the way care is delivered by focusing on the relationship between staff and service users
3	The values, principles and attitudes of staff are important to recovery-orientated care	The intervention is provided to the clinical team with a focus on promoting values and attitudes consistent with recovery-orientated practice.

Additionally, for the content specific to this thesis, the common cultural adaptations identified within Section 4.5 were applied to ensure that the intervention was culturally-sensitive. The common cultural adaptations used to guide the development of the intervention are shown in Box 6-1.

1) Explicit discussion of stigma and discrimination including the experience and impact of racism.
2) Focusing on spirituality and religion.
3) Taking a collectivist approach to identity.
4) Exploring and understanding the person's cultural background.
5) Understanding the person's illness perceptions and beliefs.
6) Ensuring the language used within the intervention is culturally appropriate.
7) Avoiding a 'one size fits all's approach within the intervention.

Box 6-1: Common cultural adaptations guiding intervention development

6.2 Method

The methods section is organised into the three stages corresponding to the objectives. The three stages of development, although presented sequentially, were iterative in nature, with frequent team discussions and input from experts included at each stage. The processes involved in each stage of the method are shown diagrammatically in Figure 6.1.

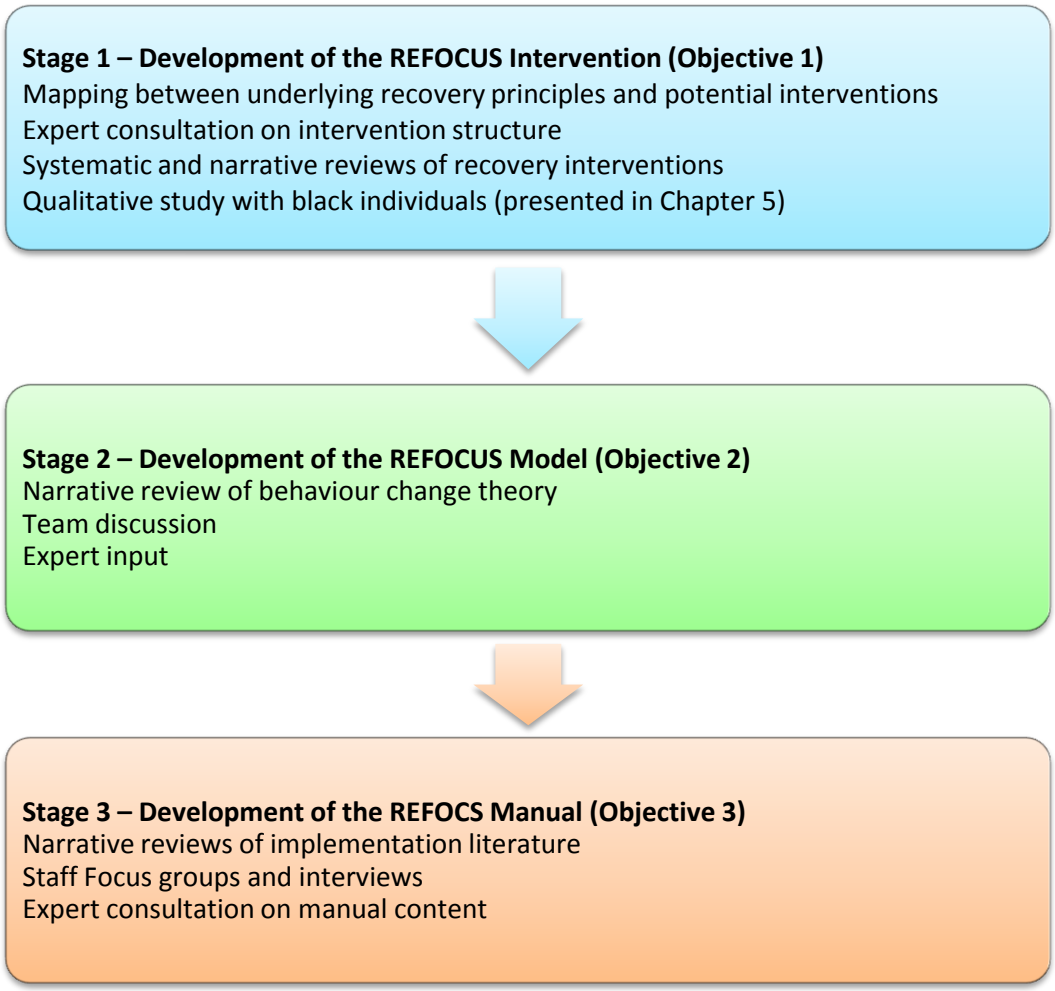


Figure 6.1: Development method

For each stage a brief overview of the general method is provided with a more in-depth focus on the areas specific to this thesis.

6.2.1 Stage 1: Development of the REFOCUS Intervention (Objective 1)

Mapping exercise using the organising frameworks

Early in the process of developing the REFOCUS intervention it became apparent that it would not be feasible to systematically review the evidence for all potential recovery-focused interventions given the breadth of the topic and the non-specificity of the term recovery. Therefore a mapping exercise was conducted which mapped the underlying recovery principles to candidate recovery approaches or interventions. For example, strengths assessments were mapped to the CHIME recovery process of empowerment, and community links to address connectedness. The mapping exercise led to the development of the REFOCUS Intervention (Version 1). The REFOCUS Intervention (Version 1) listed all the potential

components and the proposed structure of the intervention, but did not provide detail of the intervention content.

Expert Consultation - Overall structure of the REFOCUS Intervention

To maximise the validity of the intervention (i.e. to ensure that it targets personal recovery rather than another area of good practice) and to test the feasibility of implementation, the outline of the REFOCUS Intervention (version 1) was sent for consultation to the REFOCUS study committees (IAB, LEAP, Steering Group and BME virtual consultation panel) described in Section 3.2.1. Consultees were asked three questions: "Does the intervention appear feasible for implementation within the NHS?", "Is it too ambitious or not ambitious enough?" and "Can you suggest any interventions or tools for specific modules, which could be considered in the systematic reviews?". A copy of the consultation document sent to the REFOCUS committees is included in Appendix 8.

The structure of the REFOCUS Intervention, including the number of areas to include in the intervention was modified on the basis of this consultation. This led to the development of the REFOCUS Intervention (Version 2). To develop the content of the REFOCUS Intervention (Version 2), systematic and narrative literature reviews of the potential recovery interventions identified in the mapping exercise described earlier were conducted. Within the systematic and narrative literature reviews, three evaluation criteria were used. These were meaningfulness, effectiveness and feasibility. Although cost-effectiveness was originally considered as a criterion, a scoping search of the literature failed to identify any relevant economic evaluations.

Meaningfulness assessed the relevance of each identified intervention against the five CHIME recovery processes. Interventions needed to address or have an impact on at least one of the five recovery processes. Interventions which specifically focused on clinical outcomes such as symptoms, reducing relapse and rehospitalisation were only considered if they also focused on, or had a demonstrable impact on one of the five CHIME recovery processes.

The effectiveness of all existing interventions was assessed. This included assessing effectiveness in terms of improving measures of personal recovery and recovery outcomes such as hope and empowerment. Where possible, systematic reviews were used to assess evidence for effectiveness.

The final criterion was feasibility, defined as the cumulative impact of different influences which effect the implementation of an intervention [256]. Research has shown that the feasibility of an intervention impacts on evidence translation, with feasible interventions more likely to be implemented within routine practice [257,258,259]. A new feasibility measure was specifically developed for the REFOCUS study [256]. Feasibility was also assessed during the expert consultation.

The systematic and narrative literature reviews were supplemented with team discussion and advice from experts outside of the REFOCUS panels who were specifically contacted about particular elements of the intervention content.

Thesis specific Intervention component

To ensure the component developed was culturally sensitive, the common cultural adaptations presented in Box 6-1 were used to guide the development of the intervention content which was specific to this thesis. To develop this part of the intervention two data sources were used:

Data source 1 - Qualitative interviews: As analysis of the qualitative data presented in Chapter 5 was conducted concurrently with data collection, individuals in the later interviews were asked to make suggestions about the ways in which mental health services could support their recovery. Intervention suggestions were themed.

Data source 2 - Narrative literature reviews were used to review the evidence for interventions matching the themes of the qualitative analysis described above.

6.2.2 Stage 2 - Developing the REFOCUS Model (Objective 2)

It was suggested during the expert consultation that the intervention should be conceptually defensible. This is in line with the first stage of the MRC framework [31], where it is noted that any intervention should have a clear conceptual model. Within the MRC Framework, it is recommended that an intervention includes a testable model, which specifies the active components of the intervention, the intervention processes and the anticipated outcomes. The theoretical basis underlying the intervention informs the development of the intervention model. In line with the MRC guidance, the second stage of developing the intervention included the development of the REFOCUS model.

As the intervention was a team-based intervention, the level of change focused on the team, as well as changes to individual staff values and attitudes. The model also aimed to specify the anticipated changes in staff practice at both the team and individual level, and the resulting change in service user experience. Finally, the model identified the anticipated outcomes for people using the service at both the proximal and distal levels.

To develop the REFOCUS model the literature relating to behaviour change was narratively reviewed with the aim of identifying relevant theories of behaviour change. Team discussion was used to link the anticipated effects of the intervention to the behaviour change theory identified.

6.2.3 Stage 3 - Development of the REFOCUS Manual (Objective 3)

The goal of this stage was to produce a manual suitable for use within a cluster RCT (described in Chapter 7). The intervention manual was given to all staff members in the intervention teams. The manual provided details about the content of the intervention and contained resources to help staff implement the intervention. Specifically, in addition to *what* to do (the content and resources of the manual), the implementation strategies focused on *how* to do it (in this specific instance of an evaluated trial).

The content and resources included in the REFOCUS Manual (Version 1) were drafted through a process of team discussion and expert advice. The thesis author took a lead role in drafting the manual, including the component developed as part of this thesis. Frequent team meetings were held to iteratively develop the REFOCUS Manual (Version 1).

Two methods were used to develop the implementation strategies included in the manual. The strategies were informed by literature reviews, which focused on the implementation literature and focus groups with senior managers within the Trusts, team leaders and front-line clinical staff.

Expert consultation - REFOCUS Manual content

As with the outline of the REFOCUS intervention (Version 1) discussed in section 6.2.1, a consultation on the REFOCUS Manual (Version 1) was held with the REFOCUS study committees. Individuals were asked to comment on the following four areas.

1. Feasibility – is the intervention feasible in terms of time, resources and skills required to carry out each area?

2. Clarity – does the intervention make clinical sense? Is there enough information presented to allow people to carry out the intervention?
3. Presentation – is the language acceptable? Do the concepts make sense? What would be a better way of presenting each chapter? Would other layouts be more useful?
4. Applicability – How does each section fit with current practice? Are people already doing these things?

Responses received in the consultation were tabulated and themed. The themes highlighted were used to refine the REFOCUS Manual (Version 1). This led to the development of the final version of the REFOCUS Manual.

6.3 Results

6.3.1 Stage 1 - Intervention

The REFOCUS Intervention (Version 1) initially proposed organising potential interventions around points along the clinical care pathway of assessment, intervention and evaluation. The results of the mapping exercise led to the proposal of four core intervention modules and five optional modules. The four core modules included in the REFOCUS Intervention (Version 1) were "Knowledge, values and attitudes", "Strengths Assessment", "Recovery planning" and "Interpersonal style" with the five CHIME recovery processes proposed as optional modules. The core modules initially used clinical pathway terminology and were organised around the care pathway to make them accessible to staff.

Expert Consultation - REFOCUS intervention

In total 16 individuals responded to the consultation, with nine members providing very detailed comment and seven individuals providing general support for the intervention. Of the nine individuals who provided detailed comments, three were from the BME virtual consultation panel. The consultation comments received were tabulated and themed. The main themes arising from the consultation were Feasibility; Implementation, Suggested interventions or tools; Service user involvement; and Language. These themes are briefly described below.

Feasibility comments related to the challenges of implementing the intervention within the NHS. Concerns such as resources, the time needed to implement the manual and the staff skill set were included. In particular, individuals felt that the manual included too many components, and that the inclusion of core and optional modules was confusing. Linked to

feasibility were comments relating to the practical issues concerning implementation, and the need for the manual to outline implementation strategies. The themes 'Suggested interventions or tools' included potential interventions, references or areas to consider for each of the modules. For each suggestion, the primary reference was sought and collected in full text. One important theme from the consultation concerned service user involvement. This theme related not only to service user involvement in the intervention itself, but also the level of service user involvement in developing the intervention and manual. It was also felt that any training for staff undertaken as part of the intervention should involve people with lived experience. The final theme apparent in the comments concerned the language used. Individuals did not agree with the suggestion of using clinical language to ensure the intervention manual was familiar to staff. Instead, individuals felt that the language should represent and be consistent with the concept of personal recovery, for example one individual stated:

> "*I think it could be a mistake to try and dress the recovery approach in clinical language as in my experience people see through it and feel uncomfortable with it and we shouldn't be making apologies for what we are trying to achieve".*

Following expert consultation the decision was taken to simplify the intervention. The intervention outline was further refined through a process of extensive team-based discussions and through reviews of the available evidence. This resulted in a reduction in the areas covered within the intervention and a focus on only core modules. This produced the REFOCUS Intervention (Version 2).

The REFOCUS Intervention (Version 2) contained two components. The first component, Recovery-Promoting Relationships focused on the relationship between staff and service users including staff knowledge, values and attitudes. Two types of training were provided to staff members in the intervention teams to address this component of the intervention, namely Personal Recovery Training and Coaching Training.

The second component of the intervention provided practical advice and support to staff including suggested ways of supporting recovery. This component was referred to as pro-recovery Working Practices. The Working Practices were outlined in the intervention manual, and their content covered in the staff training. The two components of the intervention were aligned with the underlying recovery principles identified in 6.1. Within the REFOCUS Intervention (Version 2) an emphasis was placed on interventions addressing goals, strengths

and identity. The Working Practices (WP) component of the intervention comprised three elements: Identity (Working Practice 1: Understanding Values and Treatment Preferences), Strengths (Working Practice 2: Assessing Strengths) and Goals (Working Practice 3: Goal striving). The components of the intervention are shown diagrammatically in Figure 6.2.

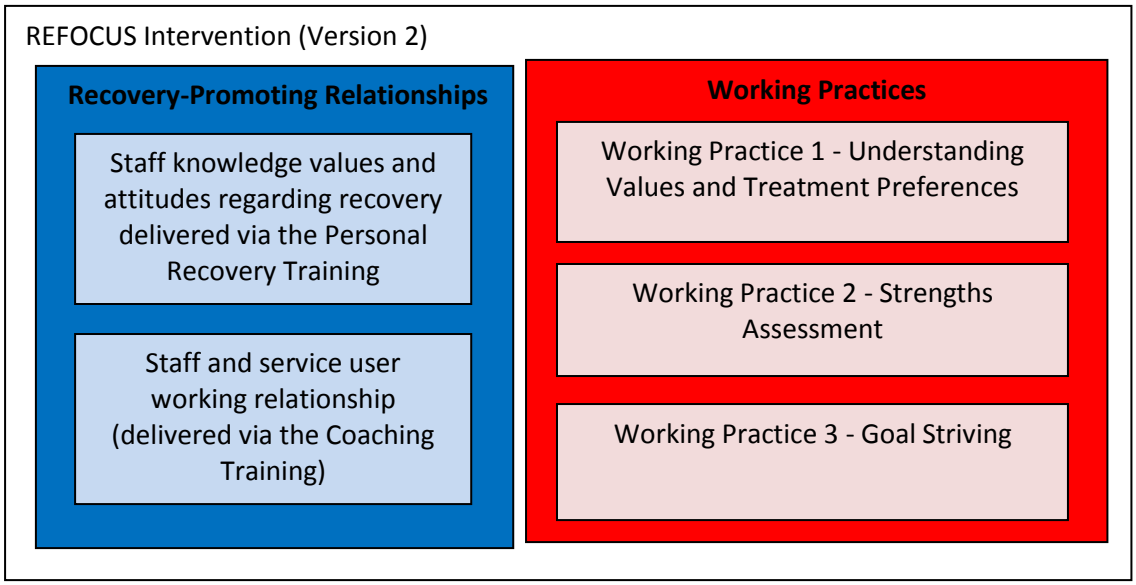


Figure 6.2: The REFOCUS Intervention (Version 2)

The intervention is now described, with particular attention given to Working Practice 1: Understanding Values and treatment preferences, which was developed as part of this thesis.

Recovery promoting relationships

The recovery-promoting relationship section focused upon *how* staff can relate to service users in a recovery-orientated way. This component of the intervention focused on:

- Core knowledge about personal recovery,
- Recovery-supporting values, attitudes and beliefs,
- Recovery-supporting interactional styles and types of relationship, and
- Coaching skills

Two areas were included in the intervention, these were i) a focus on staff knowledge, values and attitudes and ii) a focus on the working relationship between staff and service users. The recovery-supporting values, attitudes and beliefs and the core knowledge about personal recovery-focused on the elements included in the Conceptual Framework and addressed the underlying recovery principles shown in Table 6.1. This area of the intervention was covered in the Personal Recovery Training. Personal Recovery Training focused on the values and attitudes of a recovery-promoting team. The content of the training was based on the areas

included in the Conceptual Framework of Recovery. Teams received 10.5 hours of Personal Recovery Training. This was delivered as three half day sessions in months one, two and five of the intervention. The training was delivered by qualified trainers from Rethink and always included a trainer with lived experience of mental illness. In addition to focusing on the meaning of recovery as defined within the Conceptual Framework of Recovery, the training encouraged reflexive practice within the team to help team members develop a shared understanding of personal recovery.

During the mapping exercise and expert consultation, coaching skills were identified as the key focus of the Recovery-Promoting Relationships component of the intervention. Coaching skills focus on the relationship between the service user and staff member, with staff members assisting individuals to find their own solutions to enable them to reach their goals. Coaching skills were also seen as feasible and were a good fit with the Conceptual Framework thus meeting the meaningfulness criteria (described in section 6.2.1). The Coaching Training delivered to staff focused on the working relationship between staff and service users. Within the training, the REACH model of coaching which was developed by the trainers (SLaM partners) was adapted to include specific reference to the REFOCUS Working Practices. Coaching Training was provided by SLaM Partners and consisted of 14.5 hours of practical workshops. One full day followed by two half day workshops were delivered to teams in months three, four and five of the intervention. Additionally, where requested, half day booster sessions were also available to teams. Within the training, staff members were encouraged to use the REFOCUS Intervention with service users on their caseload and to discuss progress in the subsequent training sessions.

Three working practices were included in the intervention (and outlined in the intervention manual).

Working Practice 1: Understanding Values and Treatment preferences

The analysis of the qualitative study described in Chapter 5 identified themes relating to suggested interventions and ways to support personal recovery. To identify candidate items to include within the Working Practice, interventions and approaches addressing the qualitative themes were narratively reviewed. Overall, the culturally sensitive nature of the intervention was guided by the principles outlined in Box 6-1.

Qualitative findings

Individuals within the qualitative study described in Chapter 5, were asked to make suggestions about the ways in which mental health services could support the development of a positive identity or *"help you feel better about yourself."* Within the analysis, any intervention suggestions were themed.

People stressed the need to understand that individuals were made up of multiple dimensions, and that the focus should not just be on any one part of their identity. Following this recommendation, certain areas were mentioned as particularly important, these including the person's culture and background, their ethnicity, their spirituality and individual needs. The areas identified as important were categorised into nine themes. The first eight themes related to areas important to discuss with the individual namely "Race Culture and Ethnicity", "Religion and Spirituality", "Sexual Identity", "Gender", "Social Roles", "Explanatory Models of Illness", "Stigma and Discrimination", "Previous Experience of Services". Examples of some of the suggestions given by service users for the eight themes are presented below:

> *"If they don't recognise and discuss spirituality, they're blocking our path to recovery.* [SLaM focus group 2, male participant]

> *"You might find out about how much of their culture is tangled up in whatever is going on with them because nowadays you might get somebody who is a black person but they've grown up in England and their parents have grown up in England"* [Interview 12, male participant]

Individuals suggested that covering these areas may include discussing topics often outside the scope of traditional mental health services. This included attending to strengths instead of difficulties and focusing on creativity and wellbeing.

> *"But um, that's how you get the best out of somebody, by opening them up. And that should be your tool that you use to say well, 'what things are you good at? What things do you enjoy?' rather than concentrating on the problem all the time."* [Interview 12, male participant]

The final theme included in the analysis related to using the information discussed in an individualised way, and in particular focusing on "Treatment preferences". Participants noted that not all areas would be important to everyone. Further to this, individuals suggested that the information should not just be collected, but instead should be used to help understand

and meet the person's treatment preferences. This was captured in the theme "Treatment Preferences".

> *"The CPN should say these are the services that we can offer and if you feel any of them suit you or would support you in your recovery, come and access them."* [Interview 13, male participant]

People felt these types of discussions would help to reduce staff assumptions and help the individual to tell their own story. Staff listening to these experiences and allowing the person to express their own narratives was very important.

> *"I think that way they should understand the patient better and the background is very important to know the background they mustn't assume that everyone is the same; we are all different, even the white people are not the same, they need to listen to everybody"* [Interview 14 female participant]

Literature review of existing tools and intervention

Three potential types of intervention were identified which matched the qualitative findings. These were Cultural formulation tools, Explanatory model of illness guides and Person-centred planning tools.

Cultural Formulation tools

Two cultural formulation tools were identified within the literature, these were the DSM Cultural Formulation [260,261] and the Transcultural Assessment (TCA) [262].

The DSM-IV and DSM-V Cultural Formulation tool was developed to assist clinicians in identifying aspects of an individual's cultural background that are clinically relevant. The aim was to *"provide a systematic method of considering and incorporating sociocultural issues into the clinical formulation."* [[263] p9]. The DSM-V cultural formulation consists of two components the Outline of Cultural Formulation as was included in the DSM-IV and the additional Cultural Formulation Interview (CFI). The CFI includes 16 questions organised around the following 12 areas: Explanatory Model of Illness, Level of Functioning, Social Network, Caregivers, Psychosocial Stressors, Religion, Spirituality, and Moral Traditions, Immigrants and Refugees, Cultural Identity, Older Adults, School-Age Children and Adolescents, Coping and Help-Seeking, and the Patient–Clinician Relationship [264,265].

The DSM Cultural Formulation has been tested in a range of studies, mostly conducted within the USA. However, an investigation assessing its use with refugees within the Netherlands suggested that the tool was not without issues, with individuals struggling to define their own culture [266]. Experiences of using the Cultural Formulation from the clinician perspective have noted that the tool is often difficult to use within practice, with Borra noting that *"writing a case with assistance of the Cultural Formulation is very meaningful but not easy"* [[267] pS46]. A range of barriers to the routine implementation of the DSM-V version of the Cultural Formulation have been identified, including a lack of conceptual relevance, lack of clinician buy-in and ambiguity in design [268].

Transcultural Assessment Tool (TCA)

The TCA was developed by the New South Wales government with the aim of providing a guide to help clinicians conduct a culturally accurate and appropriate assessment [262]. As with the DSM Cultural Formulation, the assessment focuses on clinically relevant aspects of culture as part of the clinical and psychosocial assessment process. The TCA aims to ensure that the clinical formulations and care plans are culturally appropriate. The TCA is made up of an assessment module alongside a checklist with suggested questions and potential avenues to explore. The areas included in the TCA consist of Cultural Identity, Migration History, Cultural Perception of Mental Illness, Culturally Informed Clinical Formulation and Management/Care Plan.

The TCA provides clinicians with some underlying principles of conducting a culturally appropriate assessment, including suggestions that the clinician considers their own cultural and ethnic background, explains confidentiality and avoids making assumptions based on previous experience. At present the TCA has not been formally evaluated in a research study.

Explanatory models of Illness tools

Four qualitative tools which focus on the meaning and causes of the illness and/or explanatory models were identified within the literature. These tools are based on Kleinman's eight questions relating to explanatory models [269], and focus on the person's own idiosyncratic beliefs about the illness. In each tool, medical or technical language is avoided with the aim of encouraging individuals to talk openly about their experiences, beliefs and attitudes as well as the impact this has on different areas of their life. The qualitative tools included in the literature review were the Explanatory Model Interview Catalogue (EMIC) [270], the Short Explanatory Model Interview (SEMI) [271], the McGill Illness Narrative

Interview (MINI) [272] and the Barts Explanatory Model Inventory (BEMI) [273]. An overview of the four tools is presented in Table 6.2.

Table 6.2: Explanatory models of illness tools

Measure/ tool	Areas covered	Examples of research using the tool
EMIC [270]	Semi-structured interview containing four sections which aim to explore the person's experience of illness in their own words. The tool is not specific to mental health and includes sections on Patterns of distress, Perceived causes, Help-seeking and treatment and General illness beliefs.	The EMIC has been used in 13 different cultures. Despite being used in numerous studies for both physical and mental health, one of the problems identified within the research, relates to the feasibility of the EMIC in routine practice, particularly the time-consuming nature of the tool [274].
SEMI [271]	The SEMI aimed to overcome the feasibility issues concerning the EMIC. The tool is specific to mental health and includes five sections: Personal background, nature of the presenting problem, help-seeking behaviour, interaction with physician/paramedical, and mental illness representations. Individuals are given vignettes of common mental health problems including depression, somatisation and phobias to elicit their beliefs about such problems.	The SEMI has been tested in a comparative study of individuals using two London GP practices and primary-care centres or traditional healers in Zimbabwe [271]. The study demonstrated that the SEMI could be used as a tool to identify beliefs and expectations about illness, and that the tool could be easily used in general practice. However, the authors noted it should not be viewed as a fully comprehensive exploration of explanatory models [271] . A modified version of the SEMI was used to explore the explanatory models of people with schizophrenia from four cultural background (White British, Bangladeshis, African-Caribbean's and West Africans). One of the problems noted was the limitation of reducing explanatory models to single categories [93].
MINI [272,274]	The MINI was originally developed to investigate illness narratives in a help-seeking population with medically unexplained symptoms and focuses on how the person perceives and describes their experiences. It allows for individuals to have multiple illness representations and their illness narratives can be inconsistent and contradictory. The generic version of the MINI (version 4), contains three sections: i)narrative: unstructured section encouraging the individual to tell their story	Research using the MINI has been more limited, although a number of studies have applied the interview to migrant and minority populations within Western societies, many of which have shown the MINI to be a useful tool for eliciting different explanatory models. [272,274]

Measure/ tool	Areas covered	Examples of research using the tool
	ii)prototypes: typically relates to hypotheses about the illness or treatment iii)explanatory models: relates to causal reasoning of the person's explanatory models relating to their experience.	
BEMI [273]	To develop the BEMI, emic descriptions of an individual's perception of mental distress were identified in the literature and thematically analysed [273]. Two forms of the BEMI are available, an interview format (BEMI-I) and a checklist (BEMI-C). The BEMI-I is a semi-structured interview which includes 12 items organised into the five domains, Identity, Cause, Timeline, Consequences, and Cure/control.	Within the UK, the BEMI has been used in a number of research studies to explore the explanatory models and help-seeking strategies of individuals from different cultural backgrounds. Participants have included people from white British, Bangladeshi, black Caribbean, and Bangladeshi British participants, recruited from GP practices and community organisations, primarily with common mental disorders [273,275,276].

Person-centred planning tools

The Realising Recovery learning materials from the Scottish Recovery Network (SRN) include a person-centred planning tool to help staff get to know the person [277]. The tools also enable people to develop a personal profile or narrative. The tools provide suggestions for eight maps, covering different areas of the person's life. The maps cover relationships, important places, background, personal preferences, interests and gifts, dreams, choices, health and respect. For each map, the training materials suggest possible areas to cover. For example, it is suggested that the health map may cover what helps and damages the person's health. No formal evaluation of these training materials has been published.

Synthesis of findings

To synthesise the two data sources, the tools identified in the literature search were tabulated in Table 6.3 against the nine themes that emerged from the qualitative study.

Table 6.3: Areas covered in existing tools

Tool	Areas Covered								
	Explanatory models	Race, culture and ethnicity	Social roles	Gender	Sexual identity	Experience of mental health services	Religion and Spirituality	Stigma and discrimination	Treatment preferences
DSM -IV Cultural formulation	X	X	X				X		
Transcultural Assessment		X	X				X		
BEMI	X					X			X
SEMI	X	X	X			X			X
EMIC	X					X		X	X
MINI	X	X	X			X			X
SRN training materials		X	X	X	X				
Total	**5**	**5**	**5**	**1**	**1**	**4**	**2**	**1**	**4**

The majority of tools only focused on a few areas of the person's identity or offered only one approach to understanding the individual. In order to sufficiently cover the aspects of the Framework of Recovery Support and the suggestions from the qualitative study, it was necessary to include a wider focus to understanding the whole person and finding out what aspects of identity were important to the person. Consequently, Working Practice 1:

Understanding Values and Treatment preferences focused on understanding what was important to the individual and how these values shaped the person's treatment preferences. Issues of importance included the individual's life history, their rich identity including race, culture, ethnicity, gender, spirituality, sexual orientation and supporting the development of their personal narrative. Their treatment preferences included the kinds of support and services people want from mental health services and beyond.

As suggested in the qualitative findings and the underlying cultural adaptations, instead of utilising just one approach to understanding values and treatment preferences, it was recommended that the intervention should include a number of approaches. These were conversational, narrative or visual and were developed as part of writing the REFOCUS Manual, described in Section 6.2.3, and summarised in Table 6.5, which includes details of the provenance of each intervention component. An outline of the two other Working Practices is presented below.

Working Practice 2 - Strengths Assessment

Working Practice 2 Strengths Assessment aimed to make the strengths of a person more visible. The Working Practice included a suggested strengths assessment which focused on individual's strengths, abilities, and resources. The Working Practice also focused on how this information could be used to supplement the traditional clinical focus on deficits. A systematic review was conducting to identify existing strengths assessments for use within the intervention and has subsequently been published by the thesis author [278]. The review identified 12 strengths assessments including seven qualitative assessments and five quantitative measures of strengths. The most widely utilised and evaluated was the Strengths Assessment Worksheet [208].

The systematic review highlighted that the Strengths Assessment Worksheet developed by Rapp and Goscha [208] had the most robust evidence of effectiveness, thus meeting the effectiveness criterion. Additionally, the evidence base for the Strengths Assessment Worksheet highlighted that the assessment was feasible for routine implementation. Finally, the domains included in the Strengths Assessment Worksheet fit with the Conceptual Framework of Recovery, thus meeting the meaningfulness criterion.

Working Practice 3- Goal-Striving

The aim of the final Working Practice (goal-striving) was to enable individuals to identify and set personally meaningful goals. The Working Practice focused on helping staff and service users to work together to achieve those goals. A non-systematic literature review was conducted to identify existing goal setting and goal striving approaches. Instead of including a specific or pre-existing tool within the manual, information from this literature search was used to write guidance for goal setting.

6.3.2 Stage 2 - The REFOCUS Model (Objective 2)

The development of the REFOCUS Model was guided by two theories of change. The Theory of Reasoned Action [279,280] and the Theory of Planned Behaviour [281,282] were iteratively adapted and applied to the REFOCUS Intervention through a process of team discussion and expert advice in order to develop the REFOCUS Model. Both behaviour change theories posit that actual behaviour is influenced by behavioural intention, which is determined by attitudes and subjective norms. The Theory of Planned Behaviour also states that behavioural intention is influenced by the perceived level of behavioural control, and that behavioural control has a direct impact on actual behaviour. A meta-analysis of health research using the Theory of Planned Behaviour has indicated that over 20% of actual behaviour could be explained by components of the theory [283]. Within the REFOCUS model, elements of the Theory of Planned Behaviour were included as team values (subjective norms), individual values, attitude, knowledge, skill (behavioural control), behavioural intention and actual behaviour.

The final model for the REFOCUS Intervention is presented in Figure 6.3.

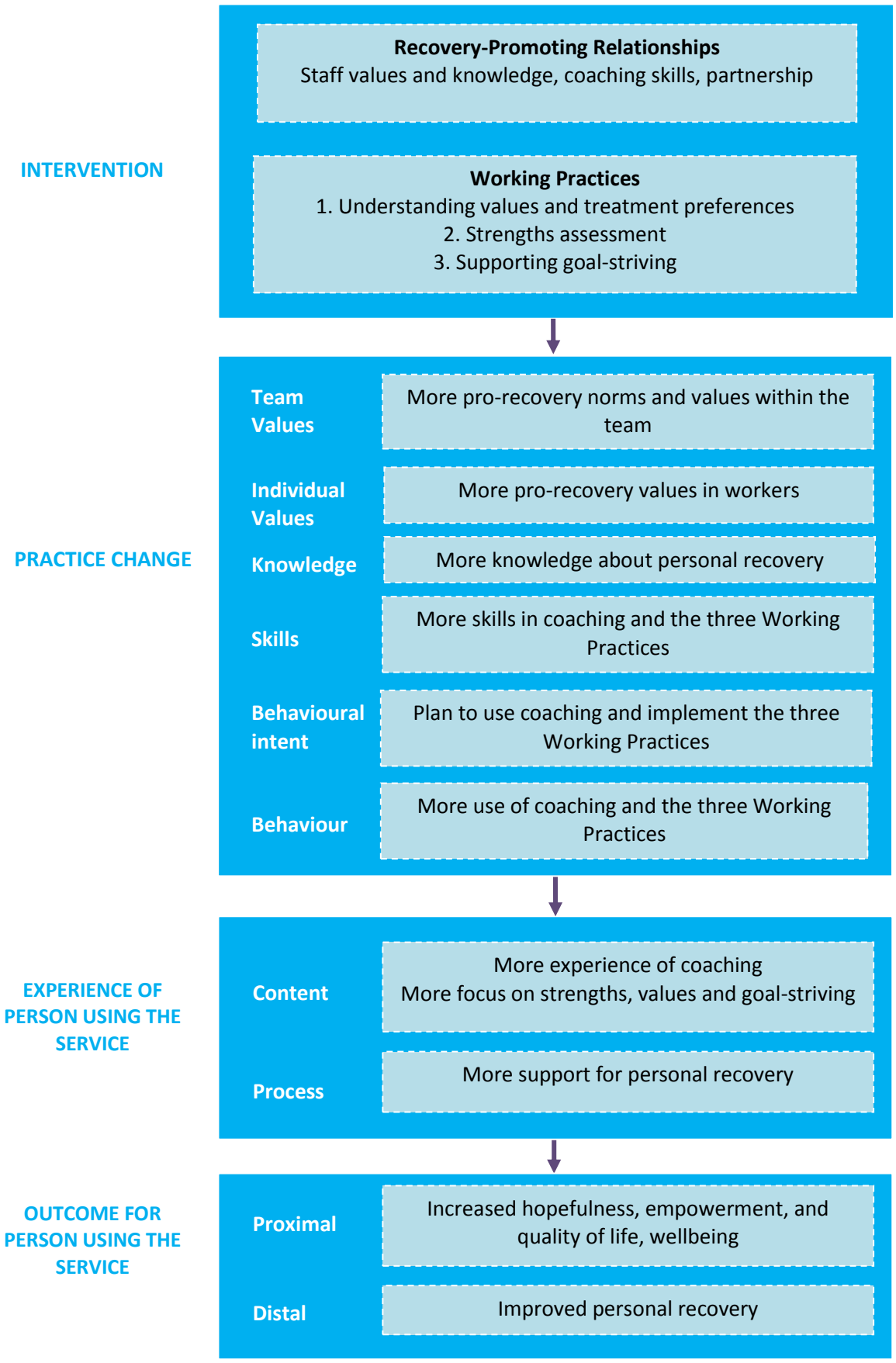


Figure 6.3: The REFOCUS Model

6.3.3 Stage 3: The REFOCUS Manual.

The REFOCUS Manual was given to all staff within the intervention teams and covered the content of the intervention. The REFOCUS Manual consisted of two components which were aligned with the REFOCUS intervention i.e. Recovery-Promoting Relationships and Working Practices. The Recovery-Promoting Relationships component of the Manual, outlined the content and ethos covered in the Personal Recovery Training and Coaching Training provided to staff members. The manual additionally included the implementation strategies which aimed to help staff implement the intervention.

Intervention Content and Resources

Each Working Practice was described using the same structure within the manual. This included describing the aim of the Working Practice and then providing staff with guidance as to how they may achieve this aim. For instance, Working Practice 2 - Strengths Assessment included a modified version of the Strengths Assessment Worksheet. Staff were also provided with additional resources to support their understanding and increase implementation. Additional resources included staff reflective activities, suggested conversation scripts and worked examples of the entries recorded on the electronic systems. The content of the REFOCUS Manual was covered in both the Personal Recovery Training and Coaching Training, where staff members were encouraged to trial the intervention resources with service users on their caseload.

The Manual content is firstly presented with a focus on Working Practice 1: Understanding Values and Treatment Preferences followed by an overview of the implementation strategies.

Working Practice 1: Understanding Values and Treatment Preferences

The manual recommended that one or a combination of approaches could be used to explore the person's values and treatment preferences. It was also stressed throughout that the areas covered should be led by the service user, with staff members open to challenging and sensitive conversations.

To help staff have a conversation about an individual's values and treatment preferences, an interview guide was specifically designed for this thesis. The Values and Treatment Preferences (VTP) Interview Guide, shown in **Box 6-2**, focuses on enabling individuals to tell their story. The aim of the VTP Interview Guide was to promote individuality and reduce staff assumptions about the person. The suggested topics included in the VTP Interview Guide

were generated from the qualitative findings and recommendations from the culturally adapted interventions review as previously discussed. For each area, prompt questions were included. Candidate items for these questions were identified from the literature and modified. For example, the questions relating to the illness experience were derived from the different explanatory model tools such as the BEMI, SEMI, MINI and EMIC, whilst the areas on culture and ethnicity modified examples found in the DSM-IV Cultural formulation and the TCA. Where an area was not covered by any existing tools, new questions were developed using suggestions made by participants in the qualitative study.

VALUES

For each area ask: What would be helpful for me to know? What is important to you?

Cultural identity including race, culture and ethnicity

How would you describe your ethnicity? Prompts: language, parents background,

Tell me a little bit about yourself and your culture Prompt preferred diet, social life, cultural behaviours, beliefs, involvement with cultural group

Religion / spirituality

Is spirituality or religion important to you? Prompts: how, in what ways?

What is your spiritual/ religious background?

How do your beliefs affect your feelings towards your mental health experiences?

Gender

Does being a <man/woman> affect the way you would like to be treated by mental health services? Prompts: how? e.g. gender of staff, type of treatment?

Sexuality

Is there anything you would like to discuss about your sexuality or that you feel is important to you? Prompts: does this impact on how services treat you?

Social roles including the family, peers and community

Tell me about your community, What role do family, friends and peers play in your life? What social roles do you have? Prompts: role in the community, social networks, caregiver, parent, peers with and without similar experiences

Meaning of 'mental illness' experience

People understand 'mental health experiences in different ways e.g. an illness, an emotional crisis, as physical illness or as a spiritual experience etc. Could you tell me what you call this experience? What do you think has caused your experience?

Previous experiences of services

What has been helpful or unhelpful about your experience of using mental health services?

Stigma and discrimination

Do people treat you differently because of mental health issues?

Have you experienced other forms of stigma or discrimination (such as racism or sexism)? Prompts: how has this affected you? Does it have an impact on the service you receive?

Other important parts of your identity

Anything else you would like to add? e.g. creative, dancer, runner, student, electrician, teacher etc.

TREATMENT PREFERENCES

In what ways do the above influence your treatment preferences, For each area above, what support if any would you like? How would you like workers to work with you?

Box 6-2: Values and Treatment Preferences Interview Guide

The second approach was the narrative approach. This approach suggested using the VTP Interview Guide to help the person write their own story or narrative. Alongside suggestions relating to the content of the narrative, the manual also provided references to online narrative resources such as the SRN Narrative Project [277] and general guidance about writing narratives.

The third proposal was the visual approach, which adapted a number of visual mapping tools available in the SRN training and learning materials [277]. The visual maps included in the manual were modified from their original form to ensure they were appropriate to the REFOCUS Manual and captured the areas of the Framework of Recovery Support. Six maps were included and are shown in Box 6-3. In addition to the suggested maps, the manual

provided clinicians with guidance relating to supporting individuals to create maps, including suggestions relating to the use of different media.

The Relationship map focused on the different relationships important to individuals with suggestions for sections such as family, friends, community, and mental health staff or providers. People were encouraged to place pictures or words relating to individuals they were close to, or who were important to them.

The Background map focuses on what life has been like for the person up until that point. One suggestion included using the map as a timeline from a certain time point such as birth or childhood to the present day. The timeline could record events and experiences significant to the individual and may also help to highlight positive experiences and achievements in addition to times of trauma, loss and grief.

The "Who am I?" map specifically focused on the person's identity and what areas of their identity were most important to them. Like the VTP Interview Guide, the map suggests including how the person's identity and their values are linked to their treatment preferences. Sections such as ethnicity, gender, culture and spirituality were all suggested inclusions.

The preferences map described the person's personal preferences, interests and gifts. People were encouraged to include what they liked as well as disliked. Although this map could be linked to mental health services, the manual also suggested widening this to include other areas of the person's life.

The choices map could be used to demonstrate areas individuals would like more control over in their lives, and the barriers they may face (re)gaining this control. Practical suggestions such as dividing the page in two to represent the service user's decisions and decisions made by other people were included in this section.

The final map included in this section of the manual revolved around one question, namely "I feel respected when…" and could be used to highlight times when the person has and hasn't felt respected.

Box 6-4: Maps including in Working Practice 1

Finally, the literature review identified two staff reflective exercises for inclusion in the manual as additional resources. The exercises proposed by Patel [284] and Sewell [9] focused on getting staff to reflect on their own culture, beliefs and behaviours, including any stereotypes they hold about their own and other people's cultures.

Working Practice 2: Strengths Assessment Worksheet

The Strengths Assessment Worksheet was identified from the systematic review as the best available strengths assessment [208,278]. Alongside the worksheet, the literature review also identified a checklist to help staff assess the strengths of service users. The checklist included suggested questions and prompts for staff to use when conducting the Strengths Assessment and was included in the additional resources section of the REFOCUS Manual.

Working Practice 3: Goal striving

Coaching was identified as the key focus of the Recovery-Promoting Relationships component of the REFOCUS intervention. The GROW model, which stands for Goal, current Reality, Options (or Obstacles) and Will (or Way forward), focuses on goal setting and attainment [285]. This model was used as the basis for the WP3 section in the REFOCUS manual.

Implementation strategies

Six implementation strategies were included in the REFOCUS Manual. These were information sharing with staff and service users, personal recovery training, coaching training, team reflection sessions, team manager reflection sessions and staff supervision forms.

The final section of the manual included details of the implementation strategies to help staff successfully implement the intervention within their own routine practice and a Gantt chart detailing the timescale of the intervention.

Expert consultation - REFOCUS Manual (Version 1)

Fourteen detailed responses plus five people responding with general support for the manual were received following the consultation period. The 14 detailed responses included three individuals from the BME virtual consultation panel, and included reference to issues pertinent to individuals from black backgrounds. The detailed consultation comments received were tabulated and themed. The main themes arising from this consultation were Service user involvement; Training practicalities; Language; Implementation issues; and Additional suggestions for the manual. These themes are briefly described below.

The theme 'Service user involvement' related to role of service users in the intervention. Individuals in the consultation felt that service users needed to be a more visible presence within the manual and that there should be a process of informing service users about the intervention. In particular, it was felt that the intervention should raise the expectations of service users to expect recovery-orientated care. It was also felt that the relationship between staff and service users was critical to the intervention and that this relationship should be built on trust, partnership and mutual respect. Training practicalities were particularly mentioned by clinicians. These comments related to the practical issues involved in setting up training for whole teams, such as cost, timing and back fill. The theme 'language' not only related to the language used in the manual and ensuring it was consistent with a recovery approach, but also the issue of including people with English as an additional language. Implementation issues related to the practical implementation of the manual within practice. Finally, consultees suggested additions to the manual, including new tools and areas to consider.

In particular, the theme of service user involvement was evident throughout the comments, with many people suggesting the need for more partnership between staff and service users. One suggestion from the consultation was that staff and service users could work together on a common goal. This led to the creation of the Partnership Project included in the Recovery-Promoting Relationships section of the manual. The Partnership Project aimed to improve the collaboration between staff and service users, promote staff and service users as equal partners in the relationship and break down any "them or us" barriers.

Following consultation the final version of the manual was produced [254]. Table 6.4 provides an outline of the areas and resources included in the REFOCUS Manual (Final Version).

Table 6.4: Areas included in the REFOCUS Manual (Final Version)

Module Content	Module Content and resources
Recovery-Promoting Relationships	Learning materials including basic areas covered in the Personal Recovery training and Coaching training. Partnership project application form Reflective exercises

Module Content	Module Content and resources
Working Practice 1: Understanding Values and treatment preferences	Introduction to understanding values and treatment preferences Information on Conversational, narrative and visual approaches Values and Treatment Preferences Interview Guide Example narratives and multimedia resources Staff reflective exercises
Working Practice 2: Strengths-based Assessment	Printable versions of the Strengths Assessment Worksheet Guidance on using the assessment tool Suggested questions and areas to cover Reflective exercises
Working Practice 3: Goal setting and goal striving	Guidance on goal setting and striving
Implementation strategies	Information sharing Details of the Personal recovery training Details of the Coaching training Team manager reflection sessions Team reflection sessions Supervision forms Example clinical information system boxes

Summary of the REFOCUS Intervention

In summary the REFOCUS intervention consisted of two components i.e. Recovery-Promoting Relationships and Working Practices. Staff within the intervention teams were given the REFOCUS Manual, which included details of the two components, and were provided with two types of training (Personal Recovery and Coaching Training) delivered throughout the intervention period. A summary of the intervention manual, including the resources used to develop each section and the adaptations made is provided in Table 6.5

Table 6.5: Summary of the REFOCUS Intervention Components

Intervention Component	Specific Intervention Content	Resources used in development	Adaptations
Recovery-Promoting Relationships	Learning materials including basic areas covered in the Personal Recovery training and Coaching training.	The Personal Recovery Training was developed by Rethink Mental Illness and based on the Conceptual Framework of Recovery [110]. The Coaching Training was based on the REACH Model developed by SLaM Partners who conducted the training.	The content of both training packages were modified for the intervention. This included specific reference to the Conceptual Framework of Personal Recovery within the Personal Recovery Training and reference to the Working Practices and REFOCUS Manual within the Coaching Training.
	Partnership project application form	REFOCUS expert committees	The Partnership project application form was developed by the REFOCUS team following consultation with the REFOCUS expert committees
Working Practice 1: Understanding Values and Treatment Preferences	Information on conversational, narrative and visual approaches to understanding values and treatment preferences	The DSM-IV and DSM-V Cultural Formulation [260,261] served as an overall guide for the format of the Understanding Values and Treatment Preferences chapter.	The Manual text was drafted by the thesis author in collaboration with the REFOCUS team. The content of this section was based on the DSM-IV and DSM-V Cultural Formulation [260,261].
	VTP Interview Guide	Two main sources were used to develop the questions included in the VTP Interview Guide. These were the Barts Explanatory Model Inventory (BEMI) [273,276] and the Transcultural Assessment [262].	The "Cultural identity", "Religion / spirituality" and "Social roles" sections of the VTP Interview Guide was based on items included in the Transcultural Assessment [262]. For each item, the language was modified to ensure it was appropriate for use within the UK.

Intervention Component	Specific Intervention Content	Resources used in development	Adaptations
			Additional prompts were added to each item. The "Meaning of 'mental illness' experience" was based on items included in the BEMI [273,276]. The prompts and examples given were modified and throughout the whole of the VTP Interview Guide, phrases such as illness were replaced by experience.
	Suggested visual maps for understanding VTP	The Scottish Recovery Network Realising Recovery Learning Materials [277] formed the basis of this section.	The titles for the different visual maps were based on the SRN Realising Recovery Materials [277]. The content and description of each visual map was adapted by the thesis author.
	Staff reflective exercises	Two staff reflective exercises were included in the manual. These were i) Understanding Staff Values Exercise adapted from Sewell [9] and ii) Staff Personal Awareness Exercise adapted from Patel [284].	The wording of both exercises were modified, although the content remained largely unchanged from the original sources.
Working Practice 2: Strengths-based Assessment	Guidance assessing the strengths of service users	The Strengths Assessment Worksheet [208] served as the basis of the Manual section on assessing strengths.	The content of the Manual was drafted by the thesis author and the REFOCUS research team.

Intervention Component	Specific Intervention Content	Resources used in development	Adaptations
	Strengths Assessment Worksheet	A systematic review of strengths assessments was used to identify the most appropriate tool [278]. The Rapp Strengths Assessment Worksheet was recommended and reproduced within the Manual [208].	The language used in the Strengths Assessment Worksheet [208] was adapted to ensure it was culturally appropriate to the UK context.
	Suggested questions and areas to cover in the assessment	The additional resources provided by Rapp and Goshca in [208] were used in the Intervention Manual.	The language used within the additional resources was adapted, and new examples added to ensure the guidance was appropriate to a UK setting.
	Reflective exercises	The exercise for workers was based on the Scottish Recovery Network Realising Recovery Materials [277].	The language of the exercise was adapted with the content remaining largely unchanged.
Working Practice 3: Goal setting and goal striving	Guidance on goal setting and striving	The Goal striving approach was based on the GROW model [285], which was linked to the Coaching Training provided to staff.	The GROW approach [285] was reproduced in the manual, with the remaining text drafted by the thesis author and REFOCUS research team.

6.4 Implications for the thesis

This chapter presented the development of the intervention component tested within this thesis. The intervention was developed in line with the MRC framework and was tested within a cluster RCT. The thesis will now focus on the evaluation of the intervention within the cluster RCT.

Chapter 7 Cluster Randomised Controlled Trial Method

7.1 Introduction

The third aim of the thesis was to test the effectiveness of the REFOCUS Intervention for individuals from black backgrounds. To achieve this aim, a cluster RCT was conducted. This chapter outlines the method for the RCT. The trial protocol has been published [27].

7.2 Design

The REFOCUS trial was a two-centre cluster RCT, with the unit of randomisation the clinical team. The trial was primarily pragmatic in approach such that it aimed to test the intervention in 'real world' conditions. For health trials assessing the effectiveness of interventions or models of care, RCTs are seen as the 'gold-standard' form of evaluation due to their methodological rigour [286]. Although the REFOCUS trial was a two-centre cluster RCT, this thesis reports on a sub-study of the main trial. The sub-study was conducted in a single centre, SLaM NHS Foundation Trust. Blocks of community teams were randomised to receive either the REFOCUS intervention or standard clinical care. The intervention was delivered to all members of the clinical team. The evaluation of the trial included both quantitative outcome assessment and a qualitative process evaluation. Although the trial approach was pragmatic, the analysis included explanatory elements, such that it aimed to explain the effectiveness of the intervention [286].

A process evaluation was nested in the trial, in line with best practice in trial methodology as discussed in Section 1.4 [51]. The method for both the quantitative outcome analysis and the qualitative process evaluation is outlined below.

7.3 Objectives and Hypotheses

The RCT had three objectives.

Objective 1: To test the effectiveness of the REFOCUS intervention for black individuals

Two hypotheses were tested:

Hypothesis 1 (recovery): Black individuals assigned to the intervention arm will experience greater improvements in recovery as measured by the QPR compared to those receiving standard care.

Hypothesis 2 (satisfaction): Black individuals assigned to the intervention arm will experience greater improvements in service satisfaction as measured by the CSQ-8 compared to those receiving standard care.

Objective 2: To understand the experience of individuals receiving the intervention.

Qualitative data collected from the process evaluation were used to investigate the experience of receiving the intervention. Although, the process evaluation covered receiving the intervention as a whole, it specifically focused on Working Practice 1: Understanding Values and Treatment Preferences.

Objective 3: To integrate the quantitative and qualitative data to validate a section of the Framework of Recovery Support.

Qualitative data included in the process evaluation was used to identify concepts for use in a SEM analysis. The path tested in the SEM was based on the suggested pathway included in the Framework of Recovery Support. Quantitative data from the trial were used to measure the concepts included in the SEM analysis.

7.4 Ethical approval and trial registration

Ethical approval was obtained from East London REC 3 approval 11/LO/0083 on 22/2/2011. The trial registration number is ISRCTN02507940 (controlled-trials.com).

7.5 Setting

The trial was conducted in the psychosis CAG within SLaM (described in Section 5.2.2). Briefly, the Psychosis CAG provides treatment and care to individuals with psychosis. Different care pathways, including 'early intervention', 'complex care' and 'promoting recovery' are implemented based on the team type, the needs of the individual and the stage of illness.

7.6 Sample

The inclusion and exclusion criteria for the trial were applied at three different levels: team, staff and service user.

Team inclusion criteria:

- Adult community mental health team
- Any team in the ‘complex care’ or ‘promoting recovery’ care pathway within the Psychosis CAG

- Provides a care co-ordinating function

Team exclusion criteria:

- Teams already heavily involved in other research projects (based on the opinion of senior management)

Staff inclusion criteria:

- Provide clinical input within a team included in the trial
- Paired staff members are required to be in regular clinical contact with service users recruited into the trial.

Staff exclusion criteria:

- Staff providing clinical input into a team allocated to the opposite arm of the trial.

Service user inclusion criteria:

- From black African, black Caribbean, black British or black other backgrounds, as recorded on the clinical information system.
- Aged 18-65 years
- Primary clinical diagnosis of psychosis including, but not restricted to schizophrenia, schizoaffective disorder and bipolar disorder
- No immediate plans for discharge
- Not currently receiving inpatient care or in prison
- Speaks and understands English
- Not participating in substantial other study
- Has participating paired staff member
- In the opinion of the clinician, is sufficiently well to participate

Service user exclusion criteria:

- Unable to give informed consent or too unwell to be interviewed (in the opinion of the clinician)
- Not in regular contact with the team

All community based teams within the Psychosis CAG were approached to take part in the study if they met the above inclusion criteria.

7.6.1 Trial sample size

The two primary outcomes were the QPR and the CSQ-8. The QPR has two subscales: Intrapersonal (mean=45.7, sd=16.1, range 13-68) and Interpersonal (mean =14.0, sd = 3.7, 0-20) [287]. The CSQ-8 produces a global score (mean =24, sd=6) [288]. The estimated effect size for the present thesis was calculated from the difference detected and resulting effect

size from a retrospective re-analysis of CSQ-8 data for black individuals included in the Alternatives study [289]. The Alternatives study was a non-randomised comparison of inpatient alternatives to traditional acute mental health inpatient care across England. The Alternatives study demonstrated an effect size of 0.67 between the intervention and control groups.

An effect size of 0.67 equates to a difference of 10.8 on the QPR intrapersonal subscale, 2.5 on the QPR interpersonal subscale and a difference of 4 points on the CSQ-8. This resulted in an estimated sample size for a 2-group comparison of means (alpha 0.05, power = 0.8) of 35 per group for the QSR and 36 per group for the CSQ-8 data.

As the trial was cluster randomised, the power calculations took account of clustering by using an intercluster correlation of 0.05 [290]. Failure to account for clustering at this stage of the trial design would result in the trial being under-powered [286]. Clustering was based on 16 teams in SLaM (assuming a 20% attrition rate from the 20 originally planned teams) and an intercluster correlation of 0.05, with equal numbers of clusters in each randomisation group. To account for clustering 44 participants per arm were required. Therefore, the aim was to recruit six participants per cluster. This allowed for an attrition rate of 7% or one participant to drop out per team.

The total anticipated sample size for the BME participants was 120 (six participants x20 teams), based on the above attrition rates and clustering, this would result in an analysable sample of 89, giving power to detect a medium to large effect size of 0.67 (alpha 0.05, power 0.8) on the CSQ-8 and QPR.

7.6.2 Process evaluation sample

The methodology used in the initial qualitative phase of this thesis (described in Chapter 5) was broadly the same as the methodology used for the process evaluation. Consequently, only brief details of the method used in the trial process evaluation are described below.

A total of ten interviews were originally planned using a convenience sample of individuals in the Lewisham, Southwark and Croydon intervention teams. In addition to the trial inclusion criteria, individuals were required to be willing and able to discuss their experience of the REFOCUS intervention. Data collection was terminated after eight interviews, as category saturation was achieved.

7.7 Control Condition

To be eligible for the trial, all teams had to provide a care co-ordinating function for service users. Since 1991, the CPA has been the framework for care co-ordination and resource allocation within the NHS [291]. The four main elements of the CPA are:

1. Systematic arrangements for assessing the health and social needs of people accepted into specialist mental health services;
2. The formation of a care plan which identifies the health and social care required from a variety of providers;
3. The appointment of a key worker to keep in close touch with the service user and to monitor and co-ordinate care;
4. Regular review and, where necessary, agreed changes to the care plan.

Individuals within teams allocated to the control arm of the trial continued to receive standard care in accordance with the CPA detailed above. This involves team-based multidisciplinary care typically comprising input from psychiatrists, community psychiatric nurses, social workers, psychologists and in some cases occupational therapists and vocational specialists.

7.8 Intervention

Individuals within teams allocated to the intervention arm received the same standard care as in the control arm, and in addition their team received the REFOCUS intervention. The REFOCUS manual was described in detail in Chapter 6. Briefly the intervention consisted of two components; Recovery-Promoting Relationships and pro-recovery Working Practices. The Recovery-Promoting Relationships component aimed to enable teams to develop a shared understanding of what personal recovery means to them and their practices as well as recognising service users as equal partners in their care. Attitude and value change were promoted through 10.5 hours of personal recovery training and 14.5 hours of coaching training. A partnership project aimed at encouraging staff and service users to work collaboratively was also included in this component of the intervention. The three pro-recovery Working Practices included understanding an individual's values and their treatment preferences, conducting and using a strengths-based assessment, and supporting personal goal-striving.

7.9 Measures and topic guides

A number of service user-rated and staff-rated outcomes were included in the trial. The CHIME recovery processes were used to identify outcome measures. Measures used within the trial included both standardised assessments and new measures developed for the trial. A copy of the baseline assessment checklist and the new measures created for the trial are included in Appendix 9.

7.9.1 Service user-rated measures

Primary outcome measures

The **Questionnaire about the Process of Recovery** (**QPR)** is a 22-item self-rated measure of personal recovery [287]. Each item is rated on a five-point Likert scale from 0 (Disagree strongly) to 4 (Agree strongly). It comprises two subscales: Intrapersonal (17 items) and Interpersonal (5 items). The QPR was developed in the UK and has been used with individuals with psychosis. Good internal consistency has been demonstrated for the intrapersonal (r=0.94) and interpersonal (r=0.77) subscales, along with good test re-test reliability (intrapersonal: r=0.87, interpersonal: r=0.77). Subscale scores were calculated by summing the items included within the subscale with overall scores calculated by combining the two subscales. Overall scores range from 0 (low recovery) to 88.

The **Client Satisfaction Questionnaire – 8 item measure (CSQ-8)** is an eight-item measure of general satisfaction with the services received. Items are rated from 1 to 4, giving a total score between 8 and 32 with higher scores representing greater satisfaction with services [288]. The CSQ-8 has been widely used within the research literature and has been validated for use with psychiatric populations [292,293]. For example, the CSQ-8 has good internal consistency when used in a sample of adults attending community mental health centres (coefficient alpha – 0.92) [294] and has good construct validity [295].

Secondary outcome measures

The **Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)** is a 14-item scale measuring wellbeing. Items are rated on a five-point scale ranging from 1 (None of the time) to 5 (All of the time. Total scores range from 14 (low wellbeing) to 70 (high wellbeing) [296].

The **Mental Health Confidence Scale (MHCS)** is a 16-item measure of empowerment rated from 1 (very non-confident) to 6 (very confident). Total scores range from 16 (low confidence) to 96 (high confidence) [297].

The **Herth Hope Index (HHI)** is a 12-item measure of levels of hope. Each item is rated on a four-point scale from "Strongly disagree" (1) to "Strongly agree" (4). Total scores range from 12 (low hope) to 48 (high hope) [298].

The **Manchester Short Assessment of Quality of Life (MANSA)** rates satisfaction with different areas of a person's life and includes 16 items. Each item is rated on a seven-point scale from 1 (Couldn't be worse) to 7 (Couldn't be better) [299].

The **Camberwell Assessment of Needs Short Appraisal Schedule – Patient (CANSAS-P)** assesses 22 domains of health and social need, with each rated as 0 (no problem), 1 (met need), 2 (unmet need) or 9 (unknown) [300].

The **Icepop Capability Measure for Adults (ICECAP-A)** measure includes five questions and rates quality of life. There are four anchor points for each of the five-questions. The anchor points are specific to the question asked [301].

Two measures of process were specifically developed for use within the trial. The **INSPIRE** (Version 3) rates the recovery-orientation of services by asking individuals to identify the level of support they have received for areas important to their personal recovery. INSPIRE contains two sub-scales, one assessing recovery-support (INSPIRE Support) and the other relationships (INSPIRE Relationships). The INSPIRE Support subscale includes 20 items. For each item the individual is first asked to rate whether that area is important to their recovery. If the area is important, individuals then rate the amount of support they receive from staff on a five-point scale ranging from 1 (Not at all) to 5 (Very much). The INSPIRE Relationships includes seven items all rated on a five-point scale from 1 (Strongly disagree) to 5 (strongly agree). Each sub-scale has a minimum score of 0 (lowest support for recovery) and a maximum score of 100 (highest support for recovery).

The **Recovery Fidelity Scale – Service User (RFS-SU)** was the second process measure developed for the trial. The RFS-SU assesses the experience of each component of the intervention. The scale covers six areas of the intervention: coaching skills, understanding values and treatment preferences, discussing strengths, identifying personally-valued goals, working towards personally-valued goals and the partnership project.

A **Sociodemographics Form – Service User (SF-SU)** records information on the individual's gender, date of birth, ethnicity, languages spoken, country of birth, education, employment, marital status, housing and length of time within mental health services.

7.9.2 Staff-rated measures

The **Health of the Nation Outcome Scale** (**HoNOS)** rates the level of social disability of the service user. It is a 12-item measure, with each item rated on a five-point scale from 0 (No problem) to 4 (severe or very severe problem) [302].

The **CANSAS-S** is the staff-rated version of CANSAS-P, with the same 22 domains, rating scale and scoring as the service user version described above. The CANSAS-S is based on the staff perception of whether the 22 items are a problem for the individual.

The **Global Assessment of Functioning scale** (**GAF)** is a two-item measure of impairment in functioning which rates both level of symptoms and level of disability on a scale from 1 (most severe) to 90 (superior functioning). The mean of the two ratings provides an overall rating of impairment due to both physical and environmental limitations, ranging from 1 (high impairment) to 90 (no impairment).

7.9.3 Researcher-rated measures

The **Brief Psychiatric Rating Scale (BPRS)** is an 18-item observer-rated measure of symptomatology. Each item is rated on a seven-point scale from 1 (Not observed / reported) to 7 (Very severe). Additionally the first ten questions can be rated 0 (Cannot be assessed) [303].

The **Client Service Receipt Inventory (CSRI)** collects cost-related information such as contact with different mental health professions, inpatient days, contact with the criminal justice system and medication use [304]. The measure was adapted for the trial to include social and mental health costs.

The **National Adult Reading Test (NART)** is a measure of pre-morbid IQ. Individuals are asked to read aloud a list of 50 words, with the researcher rating the number of errors made [305].

7.9.4 Process evaluation topic guide

A topic guide was created for the individual interviews. Throughout the topic guide a particular focus was placed on using the participants' own language to describe and explain key concepts. To achieve this, the analysis described in Chapter 5 was used to identify terms and phrases used by participants when describing their experience of recovery. The topic guide for the individual interviews aimed to gather in-depth data relating to the individual's experience of the REFOCUS intervention and included four main sections:

1. **General experience of services in the last 6-12 months:** this section aimed to find out about the individual's experience of mental health services, including any major life events or staff changes which may have occurred during the intervention period.

2. **Recovery promoting relationships:** focused on the experience of working with mental health staff. Specifically, questions enquired about the use of coaching skills and whether the language and/or content of the conversation between staff and service users had changed.

3. **Working Practices:** the main aim of this section was to elicit examples of the three Working Practices. In particular, the topic guide focused on the individual's experience of Working Practice 1: Understanding Values and Treatment Preferences. Questions and prompts explored the areas contained in the VTP Interview Guide such as ethnicity, experience of racism, spirituality etc.

4. **Other ways of supporting recovery:** the final section of the topic guide asked service users for examples of other ways that their team or care coordinator had supported recovery, and for suggestions as to how services could better support recovery.

Each section contained a number of questions and follow-up prompts which asked individuals to give examples or stories of their experience. Prompts for each question made use of the themes contained within the Framework of Recovery Support (Chapter 5) and the Conceptual Framework (Chapter 3). Data collection and analysis were concurrent, with the topic guide modified as the interviews progressed.

7.10 Procedure

7.10.1 Team recruitment and randomisation

Teams were recruited into the trial in four waves; one wave per borough. Participants were recruited over a four month period prior to randomisation, with any remaining recruitment following randomisation where necessary.

Although it was anticipated that 20 teams would be recruited, a total of 18 were eligible and consented to participate in the trial. Participating teams were randomly allocated on an equal basis to intervention (9 teams) or control (9 teams). Allocation was stratified by site (i.e. by borough) to ensure balance across the trial. Randomisation of teams was undertaken by the independent Mental Health and Neuroscience Clinical Trials Unit (CTU) in accordance with their randomisation procedures. Randomisation dates for each wave are detailed in Table 7.1.

Table 7.1: Randomisation timetable

Wave	Borough	Number of teams	Randomisation date
1	Lewisham	3	July 1st 2011
2	Southwark	6	December 1st 2011
3	Croydon	5	May 1st 2012
4	Lambeth	4	October 1st 2012

7.10.2 Participant recruitment and randomisation

The clinical information system in SLaM - EPJ, was used to generate a list of the caseload for each participating team. Lists were compiled by Mental Health Research Network Clinical Studies Officers (CSOs), to ensure researchers did not have access to patient-identifying information prior to randomisation and assent, in line with Good Clinical Practice (GCP) guidance. Individuals with a non-psychosis diagnosis were excluded. Two participant lists were then generated from this caseload list, based on ethnicity, into black (List A) or non-black lists (List B). For the purpose of this thesis, black backgrounds included individuals whose ethnicity was recorded as black African, black Caribbean, black British and black other. Where ethnicity was recorded according to country, only Caribbean and sub-Saharan African nations were included. Individuals whose ethnicity was recorded as Other African were excluded due to the lack of specificity in the term, as this may have led to the inclusion of individuals from non sub-Saharan African backgrounds. Each individual on the participant list was given a unique identification number.

In total, 37% of the Trust caseload comprised black individuals. To ensure the study had enough power to detect the anticipated effect size, and to maintain epidemiological representativeness of the REFOCUS study sample as a whole, six individuals from List A for each team were randomly selected to be included in this sub-study. List A was originally ordered by NHS number. In collaboration with the CTU, a random number list was generated via the website randomization.org for each team. The random number list was used to allocate a random number to List A participants. The list was then re-ordered accordingly.

The first six individuals on List A were contacted. If an individual did not meet the inclusion criteria specified in section 7.6, or refused consent to participate, then the next individual from participant list A was approached. Efforts were made to recruit individuals from each team, prior to team randomisation and allocation.

7.10.3 Baseline Assessment

Baseline assessments were conducted up to four months prior to randomisation for each wave. Within each participating team, relevant staff were approached to identify whether the service user randomly selected from participant list A met the inclusion criteria. Eligible service users were then asked by their care coordinator (or another appropriate member of staff) whether they were happy to be contacted by the research team. Where service users gave assent to be contacted, researchers telephoned, wrote or met with the service user face-to-face to explain the trial and provide individuals with a Participant Information Sheet. If the individual was willing to participate, a face-to-face meeting was arranged at either the team's base or at a location suggested by the service user (e.g. day care centre, person's home or location in the community).

The study was explained to the service user and informed consent obtained. service users then completed the service user-rated measures (SF-SU, QPR, INSPIRE, CSQ-8, RFS-SU, WEMWBS, MHCS, MANSA, CANSUS-P and ICECAP-A), with support from the researcher if needed. Support involved reading and filling in the forms if service users requested, or supporting the person to complete the forms by themselves. During the meeting, the researcher filled out the researcher-rated measures (NART, BPRS, CSRI). All service users were paid £10 remuneration for their participation and entered into a raffle to win a further £100.

Once the service user had completed the service user-rated measures, their care-coordinator (or another appropriate member of staff) was asked to completed the staff-rated measures (HoNOS, CANSAS-S rated and GAF) in relation to that service user.

All researchers received training in the use of the standardised measures and the research team met regularly to compare ratings and to ensure consistency of ratings across the trial.

Four months after baseline data collection began, teams were randomised into either the control or intervention arms (see Table 7.1 for schedule). Teams were allocated with a 50% likelihood of each condition. The CTU independently conducted the randomisation. Although it was intended that all baseline data be collected prior to randomisation, in cases where this was not possible, data collected continued for up to two months post-randomisation. On completed of baseline data collection, each participating team was given vouchers to a value of £100.

7.10.4 Intervention implementation

Following randomisation the intervention was delivered to the intervention arm teams for 12 months. Attendance was recorded for the coaching training, personal recovery training, team reflection sessions and team leader reflection sessions. A number of strategies were employed to aid implementation of the trial, including:

1. Adding new boxes to the clinical information system, EPJ where information relating to the three Working Practices could be recorded. Staff were encouraged to support service users to fill in the information and record conversations in the first person.
2. Separate information sessions were held for (a) staff and (b) service users and carers at the beginning of the trial. The information sessions explained in details the nature of the trial and provided some information about the intervention.
3. Team lunches were held every three months, which enabled staff in the intervention teams to reflect on their progress and to ask any questions. The team lunches also provided a visible researcher presence within the team and reminded the teams about the intervention.
4. Psychosis CAG ownership and support for the intervention which included monthly items in the CAG newsletter about the trial.
5. The research team made visits to the intervention teams to keep up a visible presence. Research members also provided teams with promotional materials such as

mugs, pens, post-it notes, mouse-mats and posters with the REFOCUS logo and information about the intervention.

7.10.5 Follow-up assessments

One year after allocation, efforts were made to contact all service users who completed the baseline assessment. Staff members were asked about the whereabouts and contact details of each individual in the trial. For service users who were no longer in contact with the team, their last known contact details were obtained and efforts made to contact them to organise the follow-up assessment. Service users who were inpatients or in prison were also followed up.

As with the baseline assessment, care coordinators or other appropriate staff members were asked to complete the staff-rated measures. Where a service user was no longer in contact with the team, staff were still asked to complete the staff-rated measures providing the person had been discharged from the team less than six months prior to the end of the trial. For service users transferred to different teams, their new care coordinator was asked to fill out the staff-rated service user specific measures regardless of whether or not their team was participating in the trial. Follow-up data collection for both staff and service users was completed by December 2013. The assessment measures used at each time point are summarised in Table 7.2

Table 7.2: Summary of assessment measures

Measure	Completion time (mins)	Baseline	Follow-up
Service user-rated measures			
SF_SU	2	X	
CSQ-8	5	X	X
QPR	10	X	X
WEMWBS	5	X	X
MHCS	5	X	X
HHI	5	X	X
MANSA	10	X	X
CANSAS-P	10	X	X
INSPIRE	10	X	X
RFS-SU	3	X	X
ICECAP-A	3	X	X
Researcher-rated measures			
BPRS	10	X	X
CSRI	10	X	X
NART	10	X	

Staff-rated measures			
HoNOS	10	X	X
CANSAS-S	10	X	X
GAF	3	X	X

7.10.6 Interview procedure

For each intervention team in the first three waves of the trial, the thesis author attended a team meeting to discuss the process evaluation with staff. Staff within each team were asked to identify and contact individuals who had experienced the REFOCUS Working Practices and who would be willing and able to take part in an individual interview. Individuals who gave assent were contacted by the thesis author and were given a participant information sheet prior to arranging the individual interview. All interviews were conducted at the team bases or in the participant's home.

Before starting the interview, verbal and written information about the study was given and informed consent was obtained for each participant. Information about demographics was collected. The interviewer stressed the confidential nature of the interview and emphasised that participants did not have to answer any questions they did not feel comfortable with and that they could withdraw from the study at any point, without needing to give a reason.

Interviews were structured around the topic guide (described in Section 7.9.4) and started with the researcher asking an open-ended question relating to the person's experience of services and the meaning of personal recovery. The interviewer used prompts from the participants to maintain the flow of the conversation and to enable an open discussion. The interview was conducted in a conversational style, with the prompts and question used flexibly to suit each individual participant. Interviews lasted between 35 and 65 minutes. At the end of the session, participants were given the opportunity to ask any questions and to reflect on their experience, before receiving £10 for their participation.

In line with a subtle realism perspective, following the interviews, I engaged in a reflexive activity to record my initial impressions of the interviews. The aim of this reflexive exercise was to assist with the data analysis and to allow any modifications to be made to the topic guide, for use in future interviews.

All interviews were recorded using two digital audio recorders and transcribed verbatim. To ensure anonymity, transcribed data was held anonymously with each participant being given a participant ID.

7.10.7 Data handling

Documentation containing identifying information such as the consent forms and contact details were stored separately from the assessment batteries and interview forms. All paper forms were stored in a locked filing cabinet only accessed by members of the research team. A password-protected database containing the participant identification numbers was stored on a secure PC at the IOPPN. All members of the research team attended the MRC GCP training and followed Research Governance arrangements.

Data were entered into a password protected Microsoft Access database. The database was set up to include validation rules for each item in the assessments. This meant that when entering data, only valid responses which matched those available on the corresponding paper measure could be entered e.g. if the scale used by the measure was rated 1 to 4, only numbers 1 to 4 could be entered into the database. To further reduce the potential for data entry errors, researchers were trained by the thesis author in data entry. To ensure consistency of data entry between researchers, data entry protocols were created which outlined the format data needed to be entered for each question. Following data entry, a process of data checking was undertaken. This involved checking a random sample of 20% of the data, stratified by site and borough, to ensure that what was entered in Access matched the paper records. All errors were recorded on a Microsoft Excel database. An error rate of less than 1% was achieved. To ensure consistency across the Access database, a process of data cleaning was undertaken. One researcher cleaned the data in accordance with a data cleaning protocol, prior to the Access data being exported into SPSS and STATA.

7.10.8 Trial Steering Committee

In line with GCP, a Trial Steering Committee was set up to oversee the implementation and conduct of the trial. The Trial Steering Committee was chaired by a psychiatrist. The committee was comprised of individuals from clinical and/or research backgrounds and included a statistician and service user representative. The Trial Steering Committee met on three occasions to discuss the protocol, procedure and progress of the trial.

7.10.9 Reporting of risk and adverse events

Throughout the trial, relevant SLaM policies regarding risk, including lone working policies, were adhered to. All serious adverse events were monitored, and the Trial Steering Committee were informed where appropriate.

7.10.10 Approaches to Minimising bias

One of the strengths of RCTs is in their methodological rigour, particularly concerning the risk of bias. Bias refers to a systematic error, which can result in either the under or over estimation of the true effects of the intervention under investigation. Bias within a trial can have an impact on both the results and their interpretation and is distinct from imprecision in the findings, which results from random error [306].

One common classification scheme for bias identifies five sources of potential bias: selection, performance, attrition, detection and reporting bias [306]. The five different sources of potential bias and the approaches taken to minimise bias within the REFOCUS trial are discussed in Table 7.3.

Table 7.3: Approaches to minimising bias

Area of bias	Definition	Approach to minimising bias taken in REFOCUS trial
Selection bias	Selection bias refers to the potential differences between the people included in the different arms of the trial. Systematic differences between the baseline characteristics of the individuals may influence the outcome. To reduce the changes of selection bias, trials should employ an adequate randomisation method and method of allocation concealment, ideally using an independent body to generate the randomisation sequence.	Randomisation of teams was undertaken by the independent Clinical Trials Unit. Random selection of service users was undertaken by the thesis author following the procedures set out by the Clinical Trials Unit. Randomisation was stratified by team location e.g. Lewisham, Southwark, Croydon and Lambeth, with equal numbers of intervention and control teams within each borough. To ensure allocation concealment, baseline data collection was completed prior to randomisation as far as possible. The author of this thesis and the trial manager were informed of the allocation by the Clinical Trials Unit.
Performance bias	Performance bias relates to systematic differences in the care received between the different arms of the trial in addition to the target intervention. Differences between the intervention and control may be due to this confounding factor and not the intervention itself.	To overcome differences in the care provided by teams within different boroughs, the clusters within the trial were stratified based on site e.g. Lewisham, Southwark, Croydon and Lambeth. Teams were clustered within the analysis and boroughs was included as a covariate to control for any differences in the care provided.
Attrition bias	Attrition bias relates to systematic differences between the intervention groups in terms of missing data. This can include people lost to follow-up as well as missing data on different outcome measures for participants retained in the trial. Any exclusions or attrition from the study should be fully described as should the approach to dealing with missing data.	Intention-to-treat (ITT) approaches were used, with all service users followed up and included in the analysis regardless whether or not they received the allocated care. The analysis also used multiple imputation to account for missing data, under the assumptions of Missing at Random (MAR) (see Section 7.11.1).
Detection bias	This source of bias relates to differences in how the outcomes are measured and detected across participants in different groups. Detection bias can occur at three levels: the	Three approaches were taken to minimise the risk of detection bias within the trial: 1) Where possible, researchers were blind to allocation

Area of bias	Definition	Approach to minimising bias taken in REFOCUS trial
	participants receiving the intervention, the personnel delivering the intervention and the researcher assessing the outcomes. If individuals are aware that they are in the intervention, they may be more likely to respond in a socially desirable way. Likewise individuals conducting the assessments, particularly where subjective measures are used, may rate the same phenomena differently according to allocation status.	status at follow-up. Participants were asked not to disclose their allocation status at follow-up. However, although this approach was possible in a small percentage of cases, due to the pragmatic nature of the intervention including the implementation strategies, it was not possible for the majority of researchers to remain blinded to allocation status. 2)Standardised outcome measures were used to reduce bias in the outcome data. 3) Protected data storage in accordance with GCP guidelines ensured that allocation and outcome data were stored separately such that allocation status was not included on the data entry database.
Reporting bias	The final source of bias relates to the reporting of outcomes. This bias may arise when researchers publish only the positive findings from the trial and do not include measures which failed to show an effect. Reporting bias may also influence the types of statistics conducted within the trial, such that multiple statistical tests are conducted, with little accounting for the problems this raises such as increased chances of spurious results [306].	A multi-method approach to evaluation which included staff, service user and researcher-rated outcome measures. The process evaluation also aimed to capture the experience of the intervention. All measures included in the outcome evaluation were clearly listed *a priori* within the trial protocol which included stating which measures were classed as primary outcomes.

7.11 Data analysis

7.11.1 Quantitative outcome evaluation

The analysis was conducted in STATA version 11. Prior to data analysis, the validity of the data was assessed in two ways. Firstly, the completeness of the data was assessed to determine whether there were any patterns of missing data, and to confirm whether data met the MAR assumptions required for data imputation. Secondly, the spread of the data was tested. Histograms were used to visually assess the spread of the data and Box plots were additionally used to help identify any outliers. Data spread was also tested numerically by assessing skewness and kurtosis. Skewness relates to the level of symmetry in a distribution. Kurtosis is a measure of the peakedness of the distribution. Both were assessed using the STATA command **tabstat [varlist], statistics(mean median skewness sd kurtosis) by(Intervention) columns(variables)** If the distribution is symmetric then the coefficient of skewness is 0. A negative coefficient indicates that the distribution is skewed to the left, and a positive coefficient right skew. The kurtosis coefficient measures the flatness of the distribution, with a smaller coefficient indicating a flatter distribution. A normal distribution has a kurtosis coefficient of three. The Shapiro-Wilk test was used to confirm whether data significantly deviated from the normal distribution.

Within the analysis, an ITT approach was applied such that the analysis is as per randomisation. This ITT approach evaluates the effects of random allocation, regardless of whether or not the participant received their allocated intervention, i.e. once intervention always intervention. The Complier-Average Causal Effect (CACE) is often used to supplement ITT analyses within individually randomised controlled trials. This approach to the analysis involves an ITT estimate for a sub-group of participants within the intervention arm, who received the intervention. Although supplementing ITT analyses with CACE is preferable, this approach is problematic within clustered RCTs as lack of fidelity to the intervention can occur at different levels, e.g. whole teams, individual staff or individual service users [286]. Therefore CACE was not used within the present thesis, given the small number of participants per cluster, which would make clustering within the CACE analysis problematic.

Another issue considered within the main analysis was that of missing data. Missing data can be classified into three groups: Missing Completely At Random (MCAR), Missing At Random (MAR) and Missing Not At Random (MNAR) [286]. When the probability of data being missing is not dependent on any observed or unobserved variable, this is classed as MCAR. In this

case, a completer analysis is seen as valid as there are no differences between the data collected and the data missing. Within a trial, MCAR is unlikely, and data are more like to be MAR or MNAR [307]. When the probability of data is determined by observed values, then the data is said to be MAR. In this case, unobserved values do not determine whether the data is missing, instead it is assumed that data is missing for a random reason. Consequently, the observed values can be used to impute data for the missing values [286]. Finally, where the reason for observations being missing is still dependent on unobserved or unknown values and cannot be accounted for by the observed values, the data is MNAR. Within the analysis, it was assumed that data was MAR. To test this assumption, firstly the amount of missing data was assessed using the STATA command **mdesc**. The STATA command **mvpatterns [varlist]** was then used to assess whether there were any patterns of missing data, which may suggest that the data were not MAR.

For the main analysis of treatment effect, pro-rating of measures was used to deal with missing data. Pro-rating is used when a person has missing scores on individual items within an otherwise completed scale. Pro-rating replaces the missing item score with the mean of the individual's completed items. As pro-rating uses information available for the individual, instead of the whole sample, it is an efficient and robust method. Where scales had existing rules regarding pro-rating, these were applied. For questionnaires with more than 20% missing responses the second approach, multiple imputation was used as a sensitivity analysis. Multiple imputation allows for the strict ITT sample including all participants to be used within the sensitivity analysis.

Multilevel mixed-effects linear regression models were developed to assess the main treatment effect of the intervention (after controlling for a range of covariates) on the two primary outcomes. Multilevel mixed-effects models were preferred over univariate t-tests which cannot control for clustering. Failure to control for clustering can result in spurious findings, such as non-significant differences between intervention and control groups reaching statistical significance due to differences in the teams (clusters) [286]. The rationale for conducting a multilevel mixed-effects analysis is that data from one cluster may be more similar than data from another cluster or team. Multilevel modelling can adjust for this dependency by the inclusion of clustering terms. In particular, this allows for the correct estimation of the standard errors [308]. When using single-level models, such as t-tests, the standard errors are more likely to be over-estimated. Multilevel modelling allows for the effect of clustering at the team level to be included in the model as a random variable, with

fixed effects for the outcome variables and covariates. Fixed effects in this case are analogous to standard regression coefficients. Random effects allow for an individual's pattern of responses to depend on many characteristics of that individual including some that are unobserved (e.g. random) [309].

To understand the impact of clustering, the level of dependency is measured. Dependency within the data is measured by the intraclass correlation coefficient (ICC).The ICC measures the percentage of variability seen in the outcome variable that is due to cluster differences. The ICC additionally adjusts for the residual variability - the variation in the outcome measure not caused by clustering - by the inclusion of covariates within the model [309].

Within the multilevel mixed-effect regression models, clustering was controlled for at the team level. Individuals may also have been clustered at the staff level (e.g. the care coordinator within a team). However, due to the large number of staff members, the majority of clusters at the staff level had only 1-2 participants per cluster, therefore no adjustment for clustering at the staff level was made. Furthermore, individuals may also have been clustered at the wave level, e.g. teams within one wave may be more similar than teams within another wave. To capture this variability, clustering within the data was conducted at the team level, with wave added as a covariate.

The model was fitted using maximum likelihood as these procedures are robust in the presence of missing data. Within STATA a mixed-effects regression model using maximum liklihood can be fitted using the **xtmixed** command. The following command is used: **xi: xtmixed [varlist] ||[cluster variable], mle.** In this case, the **xi:** command allows for categorical variables to be added within the model (e.g. accommodation, education, intervention group etc.). One disadvantage of the xtmixed command is that within STATA version 11, xtmixed is unable to provide robust standard errors. Robust standard errors allow for the assumption of homoscedasticity to be violated. Homoscedasticity was tested when assessing the assumptions of the regression models.

Four theoretically driven models were tested for the two primary outcomes. These are displayed in Table 7.4.

Table 7.4: Models tested within the regression analyses

Model No.	Intervention Group	Sociodemographics	Clinical covariates	Recovery covariates
Model 1	Included			
Model 2	Included	Included		
Model 3	Included	Included	Included	
Model 4	Included	Included	Included	Included

Model fit was tested using the Akaike's Information Criteria (AIC). As the models were nested, direct comparison was permitted to find the model with the best fit. The AIC comparisons were AIC, Delta AIC and likelihood measure. The Delta AIC shows the difference in AIC scores between each model. The best model is used to calculate the likelihood measure, which indicated the likelihood of the model being the best fit compared to the other models.

Following the identification of the best fit model, the assumptions of the linear regression models were tested. Where these assumptions are violated, the estimates from the regression are likely to be biased and inefficient [308]. Six main assumptions were identified in the present analysis method. These are 1) outcome data are linear, 2) the level-1 (individual level) residuals are normally distributed, 3) there is homogeneity of variance (homoscedasticity), 4) the independent variable is not correlated to the error term (independence of error terms), 5) predictor variables are not significantly correlated (multicollinear) and 6) individual observations do not have a large influence on the estimates of the coefficient [309]. Assumptions were tested through the use of scatter plots, which plotted the residuals against the predicted values.

To test the robustness of the synthesis a pre-planned sensitivity analysis was conducted. For the sensitivity analysis, a strict ITT sample, including all participants was used. Missing data was estimated using multiple imputation. Multiple imputation assumes that data are MAR, and that information available for the other variables can be used to estimate the individual's response on other items. Multiple imputation was conducted using the **mi impute chained** command. This command uses chained equations and Markov Chain Monte Carlo methods to calculate the estimates. One advantage of the chained method of imputation is that it allows for the inclusion of linear and logistic regression. Therefore within the imputation model the STATA code **mi impute chained (regress)** was used for the continuous variables with **(ologit)** and **(logit)** used for the ordinal and categorical variables (e.g. education, employment, relationship status) included in the imputation model. Sensitivity analyses comparing

completer and imputed analyses were conducted to test the validity of the assumptions made and the robustness of the analysis.

7.11.2 Qualitative process evaluation

As with the qualitative data discussed in Chapter 5, the process evaluation interview transcripts were coded using nVivo qualitative data analysis software version 9. Thematic analysis was used for the data analysis following the guidance of Braun and Clarke [144]. For more details of the approach see Section 5.2.6. The process evaluation was conducted as part of the wider process evaluation for the REFOCUS trial, which included individuals who were from black and non-black backgrounds. A subgroup-analysis was conducted for individuals who self-ascribed their ethnicity as black. For the whole sample, the transcripts were initially coded inductively to identify free codes and pertinent themes within the text. To ensure the perspectives of black individuals within the process evaluation, three of the four interviews used to develop the initial coding framework included individuals from black backgrounds. Following this initial inductive approach, the themes were organised into a coding framework, which considered the aims of the process evaluation, the areas previously identified within the Framework of Recovery Support and the different elements of the intervention.

To improve the reliability and validity of coding, two raters (always including the thesis author) independently coded each interview transcript. The thesis author used the initial coding framework (hence further developing it) to code the interviews conducted with black participants. Following coding, the raters met to discuss the basic codes and discussed the development of the coding framework. Any differences in coding were discussed and alternative interpretations of the data recorded as memos. Particular attention was paid to deviant cases not fitting the coding framework; these were coded as free codes within nVivo. The coding framework was developed iteratively by the thesis author. The final coding framework was then applied to all interviews conducted with black participants. All themes presented in the results (Section 8.3) included quotes and data for people from black backgrounds. Where a theme did not include any data from black participants it was removed from the coding framework. For each of the categories included in the framework, a definition was created and stored within nVivo 9 to ensure consistency of coding between the transcripts. The language of the original data extracts was used to inform their headings and definitions of each category within the framework [144].

7.11.3 Structural equation modelling (SEM)

An exploratory analysis was conducted to integrate the qualitative and quantitative data. This analysis aimed to validate a component of the Framework of Recovery Support. The exploratory analysis used SEM conducted within AMOS (version 20). SEM allows for the simultaneous testing of all the different associations between the variables included within a model, and allows us to test both the direct and indirect effect of a combination of different variables on an outcome.

Data from the qualitative process evaluation were used to identify important concepts to include within the SEM analysis. The path (i.e. the relationship between the concepts) tested within the SEM analysis was determined by the Framework of Recovery Support. This is discussed in more detail in section 8.4 of the results following presentation of the qualitative process evaluation data. The *a priori* assumptions of the SEM analysis based on the Framework of Recovery Support suggests that using Working Practice 1: Understanding Values and Treatment Preferences to help individuals regain a positive sense of self would be associated with greater satisfaction with care and improvements in personal recovery.

Two models were included in the SEM analysis. Model one included only a direct effect of exploring values and treatment preferences on satisfaction, and a direct effect of satisfaction on recovery. Model two included a direct effect of exploring values and treatment preferences on both satisfaction and recovery, in addition to the direct effect of satisfaction on recovery.

To assess the significance of the direct effects, unstandardised and standardised regression coefficients were calculated in the SEM analysis. Unstandardised regression coefficients indicate the absolute effect of one variable on another. As most scales are scored differently, unstandardised regression coefficients cannot be used to compare different variables within the analysis e.g. a one point increase in a five-point scale is different to a one point increase in a 20-point scale. To overcome this limitation, standardised regression coefficients, which express the coefficient in terms of the associated standard deviation, were also reported.

To assess the significance of the indirect effects, Sobel's test was conducted. Although Bootstrapping is usually preferred over Sobel's test as it is more robust, bootstrapping within AMOS cannot be conducted where there is missing data. As the dataset for the present

analysis including some items that were missing across participants, Sobel's test was conducted.

The AIC measure within AMOS was used to test the overall fit of the model to the data. Model fit was tested using Chi^2 goodness of fit test, Comparative fit index and Root mean square residual (RMR).

Chapter 8 Results

8.1 Introduction

This chapter presents the results of the cluster RCT described in chapter 7. The cluster RCT had three objectives. These were Objective 1) to test the effectiveness of a recovery-focused intervention for people from black backgrounds; Objective 2) to understand the experience of individuals receiving the intervention and Objective 3) to integrate the quantitative and qualitative data to validate a section of the Framework of Recovery Support. The quantitative trial results will first be presented to address Objective 1. This is followed by the qualitative results of the process evaluation which were used to address Objective 2. To integrate the data sources (Objective 3) qualitative and quantitative data from the trial were combined in an SEM analysis.

8.2 Quantitative analysis

8.2.1 Participant characteristics

A pre-planned sub-group analysis of the main trial recruited from the SLaM study site is reported within this thesis. In total, 110 individuals were included in the sub-group analysis of black individuals. The follow-up rate for the study was 73.6% (n=81). The follow-up rate did not significantly differ from the follow-up rate for the non-black participants included in the whole REFOCUS trial (75.1%, p=0.77). The following analysis relates to the sub-sample of black individuals only. The flow diagram is shown in Figure 8.1.

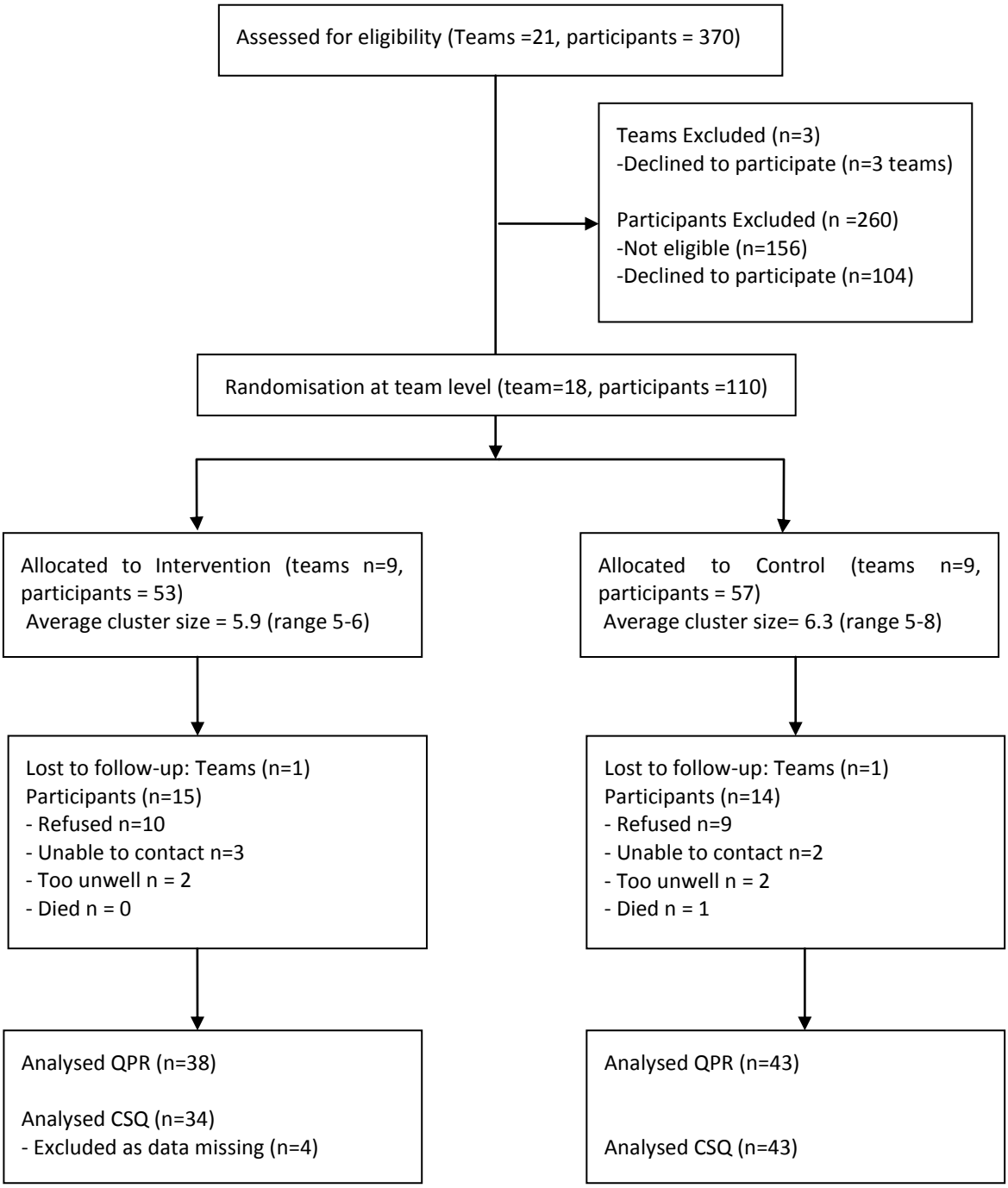


Figure 8.1: Participant Flow diagram

Teams were recruited in four waves based on borough locality (Lewisham, Southwark, Croydon and Lambeth). The number of teams varied between the boroughs. Teams were randomised in blocks to either the intervention or control. Table 8.1 shows the number of participants recruited per team and the team allocation status.

Table 8.1: Participants by team (n=110)

Team	Allocation Status	Number of participants
Borough (wave) 1		

Team	Allocation Status	Number of participants
Southbrook Road Support & Recovery (S&R)	Intervention	6
North East Lewisham S&R	Control	8
Speedwell S&R	Intervention	8
Borough (wave) 2		
Southwark North East S&R	Control	5
St Giles Central S&R	Intervention	6
St Giles South S&R	Control	6
St Giles North West S&R	Intervention	6
Southwark Community Forensic	Intervention	5
Southwark Supported Living	Control	8
Borough (wave) 3		
Croydon East Community Psychosis	Control	5
Croydon West Community Psychosis	Control	6
Low Intensity Treatment Team	Intervention	5
Croydon Community Forensic	Intervention	6
Croydon Recovery & Rehabilitation	Control	6
Borough (wave) 4		
Lambeth North Psychosis S&R	Intervention	5
Lambeth South Psychosis S&R	Intervention	6
Placement, Monitoring and Support	Control	7
Lewisham Community Forensic	Control	6

The sociodemographic characteristics and baseline variables of the sample are shown in Table 8.2

Table 8.2: Baseline characteristics (n=110)

Variables	Intervention n=53	Control n=57	Total N=110	Between group p-value
Sociodemographic variables				
Age (mean, SD)	42.9 (9.0)	43.6 (11.2)	43.2 (10.2)	0.736
Gender (n, %)				
Female	14 (26%)	23 (40%)	37 (34%)	0.122
Male	39 (74%)	34 (60%)	73 (66%)	
Ethnicity (n%)				
Black African	10 (19%)	14 (24%)	24 (22%)	0.266
Black Caribbean	34 (64%)	33 (57%)	67 (61%)	
Black Other	0 (0%)	1 (2%)	1 (<1%)	
Other	9 (17%)	10 (17%)	19 (17%)	
Time in MH services, years (mean, SD)	13.7 (8.5)	15.2 (10.2)	14.6 (9.4)	0.388
Employment (n, %)				
Competitive employment	4 (7.5%)	1 (2%)	5 (4%)	0.145
Not employed	49 (92.5%)	56 (98%)	105 (96%)	
Education (n, %)				
No formal qualifications	14 (26%)	18 (32%)	32 (29%)	0.512
GCSE or higher	39 (74%)	38 (68%)	78 (71%)	
Accommodation				
Independent	38 (72%)	32 (56%)	70 (64%)	0.235

Variables	Intervention n=53	Control n=57	Total N=110	Between group p-value
Supported	12 (23%)	17 (30%)	29 (27%)	
Homeless / Roofless	3 (5%)	7 (12%)	10 (9%)	
Marital status				
Single	43 (81%)	46 (81%)	89 (81%)	0.490
Married / Co-habiting / Civil partnership	6 (11%)	4 (7%)	10 (9%)	
Divorced / separated	3 (6%)	6 (11%)	9 (8%)	
Widowed	1 (2%)	0 (0%)	1 (<1%)	
Hospitalised in previous 6 months	6 (12%)	4 (8%)	10 (9%)	0.432
Service-user rated measures				
Baseline variables (mean, SD)				
QPR	59.4 (9.2)	57.0 (10.6)	58.1 (10.0)	0.223
CSQ-8	24.0 (5.2)	25.1 (4.7)	24.5 (5.0)	0.281
RFS-SU	2.0 (0.6)	1.8 (0.62)	1.9 (0.6)	**0.045**
HHI	35.3 (5.1)	35.9 (4.7)	35.6 (4.9)	0.553
MANSA	4.6 (1.0)	4.7 (0.9)	4.7 (0.9)	0.726
INSPIRE Support	64.9 (21.8)	56.8 (19.3)	60.9 (20.3)	**0.043**
INSPIRE Relationships	73.8 (17.2)	74.3 (15.8)	74.2 (16.5)	0.898
MHCS	66.8 (15.6)	66.3 (14.5)	66.4 (14.9)	0.875
WEMWBS	47.6 (9.1)	47.0 (10.4)	47.3 (9.8)	0.776
ICECAP-A	0.7 (0.3)	0.7 (0.2)	0.7 (0.3)	0.767
CANSAS-P (met need)	3.3 (2.7)	3.6 (3.5)	3.5 (3.1)	0.566
CANSAS-P (unmet need)	4.2 (3.3)	4.3 (2.8)	4.2 (3.0)	0.864
CANSAS-P (no need)	14.6 (4.0)	14.1 (4.5)	14.3 (4.2)	0.581
Researcher rated measure				
BPRS	33.4 (9.2)	32.1 (7.9)	32.7 (8.6)	0.457
NART Total IQ	101.8 (14.0)	97.1 (16.2)	99.4 (15.3)	0.174
Staff-rated measures				
GAF	68.7 (13.9)	64.3 (14.0)	66.5 (14.0)	0.111
HoNOS	7.5 (4.1)	10.8 (6.8)	9.2 (5.9)	**0.003**
CANSAS-S (met need)	5.7 (3.8)	5.1 (3.0)	5.4 (3.4)	0.378
CANSAS-S (unmet need)	2.8 (2.1)	3.9 (2.9)	3.4 (2.6)	**0.039**
CANSAS-S (no need)	13.5 (3.7)	13.0 (3.9)	13.2 (3.8)	0.567

Key: Bold = p<0.05

T-tests, two-group proportion tests and X^2-tests were conducted, as appropriate, to assess any differences in baseline characteristics between the intervention and control groups. There were no baseline differences between the groups on any sociodemographic variables. The service-user rated recovery fidelity scale (RFS-SU) and the INSPIRE Support subscale and the staff-rated CANSAS unmet need were significant at the 0.05 level, however, the differences were no longer significant when applying the Bonferoni correction for multiple testing. The HoNOS remained significantly different between the intervention and control groups with the control group scoring higher (indicating more problems as rated by staff) despite controlling

for multiple testing. Consequently, all but the unadjusted multilevel mixed-effects linear regression models (see Section 8.2.3) controlled for the HoNOS scores at baseline.

8.2.2 Data validation

Data validity was assessed in two ways i.e. data completeness and data spread.

Data completeness

As shown in Figure 8.1, 81 participants (73.6%) were followed up. One participant in the control team died during the study period and was subsequently excluded from all analyses. As described in Section 7.11.1, for the main analysis of treatment effect, data were pro-rated. Data completeness varied across the different measures from n=97 (88.2%) for the staff-rated GAF to n=67 (60.9%) for the BPRS. The number of participants per measure at follow-up, with full data after pro-rating is shown in Table 8.3.

Table 8.3: Number of participants per measure

Measure	Intervention (n)	Control (n)	Total (n)
Service user-rated			
QPR	38	43	81
CSQ-8	34	41	75
RFS-SU	31	38	69
HHI	33	38	71
MANSA	32	38	70
INSPIRE Support	36	42	78
INSPIRE Relationships	33	41	74
MHCS	32	37	69
WEMWBS	32	38	70
ICECAP-A	31	34	65
CANSAS-P (met need)	32	40	72
CANSAS-P (unmet need)	32	40	72
CANSAS-P (no need)	32	40	72
Researcher-rated			
BPRS	30	36	66
Staff-rated			
GAF	42	50	92
HoNOS	42	50	92
CANSAS-S (met need)	42	52	94
CANSAS-S (unmet need)	42	52	94
CANSAS-S (no need)	42	52	94

Data spread

Data spread was assessed in three ways. First, visual inspection of the histograms indicated that the majority of follow-up variables were approximately normally distributed. However,

the CSQ-8 and INSPIRE Relationships data were positively skewed and the BPRS and HoNOS were negatively skewed.

Second, box plots were used to identify any potential outliers. The box plots indicated that between 0 and 3 outliers were identified across the different scales. The outliers were checked against the paper assessments which confirmed that they were not a result of data transcription errors.

Finally, skewness and kurtosis were assessed, which confirmed the results of the histogram and box plots. The Shapiro-Wilk test indicated that the CSQ-8, INSPIRE Relationships and CANSAS-S (unmet need) all significantly deviated from the normal distribution. However, one of the advantages of multilevel modelling using regression is that it is robust against the assumption of normality as long as the residuals are normally distributed. As these data validation checks suggested that some of the variables were not normally distributed, the residuals from the regression models were plotted to ensure that the assumptions of the regression were not violated. This is presented after the results of the regression analysis in Section 8.2.3. Consequently, multilevel multivariate mixed-effects linear regression was seen as appropriate and was conducted to test for the treatment effect within the main ITT sample.

The measures of skewness, kurtosis and the results of the Shapiro-Wilk test for each outcome are included in Appendix 10.

8.2.3 Main treatment effect

To assess the main treatment effects, multilevel mixed-effects linear regression controlling for clustering at the team level, was conducted. Four theoretically driven models were fitted for the two primary outcomes (described in 7.11.1). As discussed in section 8.2.1, baseline HoNOS was significantly different between groups so was added as a covariate to all but the unadjusted model (Model 1). The coefficients, standard error and p-values obtained from each model for the QPR are shown in Table 8.4. Table 8.4 shows the impact of each baseline variable on the QPR scores at follow-up. This allows us to see what covariates have an impact on endpoint scores Within the analysis, both staff and service user-rated CANSAS (no need) were omitted from the models due to collinearity. Within the table a bold figures represents a significant results at the 0.1 level and an * at the 0.05 level.

Table 8.4: Regression values for the four adjusted models (QPR) (n=81)

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 2)	p-value	Coefficient (Model 3)	p-value	Coefficient (Model 4)	p-value
Intervention	.878	.770	-1.146	.663	-4.582	.055	-4.934	.167
Baseline QPR			.740	**<.001***	.741	**<.001***		**<.001***
Socio-demographic variables								
Age			-.1100	.360	-.0343	.770	.0187	.929
Borough			-.767	.603	-.708	.593	-.468	.814
IQ			.145	.125	. 136	.104	.170	.154
Gender			-2.479	.320	-2.219	.324	.397	.915
Employment			4.912	.312	4.317	.336	3.331	.576
Education			-.537	.878	-5.605	.088	-5.013	.276
Relationship status			.0743	.986	.258	.946	1.270	.789
Accommodation			-.058	.975	-.0192	.991	.153	.276
Clinical variables								
Time in services					-.204	.155	-.218	.305
CANSAS-P (met need)					.139	.640	.138	.680
CANSAS-PP (unmet need)					-.728	.105	-.356	.590
BPRS					.281	.110	.236	.247
GAF					.162	.205	.118	.503
HoNOS*			-.439	0.144	-.764	**.029***	.768	**.074**
CANSAS-S (met need)					.805	**.045***	.624	.282
CANSAS-S (unmet need)					2.00	**.001***	1.572	**.064**
Hospital admission					5.15	.204	4.041	.518
Recovery variables								
CSQ-8							.213	.537
HHI							-.321	.482
MHCS							-.066	.677
MANSA							.179	.954
RFS-SU							.323	.913
WEMWBS							.093	.730

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 2)	p-value	Coefficient (Model 3)	p-value	Coefficient (Model 4)	p-value
INSPIRE Support							-.001	.996
INSPIRE Relationships							.008	.946

Model fit was tested and compared across the models using three fit indices AIC, delta AIC, likelihood, shown in Table 8.5.

Table 8.5: AIC comparisons of the four models for the QPR

Model Number	AIC	Delta AIC	Likelihood
1	468.47	108.92	0.00
2	373.99	14.44	0.00
3	363.99	4.43	0.11
4	359.55	0	1

The fully saturated model was the best fit to the data as measured by the AIC and Delta AIC. The likelihood measure indicated that there was only between 0-11% chance that Model 1 -3 were a better fit than Model 4. However, one criticism of the AIC as a measure of model fit is that the more complex models with a greater number of variables often result in a better AIC score compared to less complex models. The robustness of the model will be further tested in sensitivity analyses presented in Section 8.2.4.

Interpretation of the multilevel mixed-effects linear regression analysis for the QPR

Within all models, there was no effect of intervention group on the QPR. Within Model 4, which was the best fitting model, the only significant predictor of endpoint recovery scores (QPR) was baseline recovery scores.

Table 8.6 presents the effect of each variable on the CSQ-8 scores at endpoint. The coefficients, standard error and p-values obtained from each model for the CSQ-8 are shown in Table 8.6. Table 8.6 show the impact of each variable on the CSQ-8 scores at follow-up. This allows us to see what covariates have an impact on the endpoint score. Within the analysis, both staff and service user-rated CANSAS (no need) were omitted from the model due to collinearity. Within the table, a bold figures represents significance at the 0.1 level, and an * at the 0.05 level.

Table 8.6: Regression values for the four adjusted models (CSQ-8) (n=78)

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 2)	p-value	Coefficient (Model 3)	p-value	Coefficient (Model 4)	p-value
Intervention	.093	.946	-2.394	.068	-3.347	**.009***	-3.317	**.001***
Baseline CSQ			.660	**<.001***	.537	**<.001***	. 423	**.003***
Socio-demographic variables								
Age			-.062	.237	-.019	.721	.117	**.017***
Borough			-1.789	**.015***	-2.332	**.001***	-.203	.702
IQ			.0324	.445	.0464	.224	.145	**<.001***
Gender			.565	.605	1.616	.103	5.380	**<.001***
Employment			-.162	.942	1.395	.533	-1.327	.345
Education			1.275	.437	.222	.892	.9473	.462
Relationship status			1.535	.374	2.673	.113	4.394	**<.001***
Accommodation			-1.092	.217	-.971	.259	-.164	.787
Clinical variables								
Time in services					-.076	.239	-.268	**<.001***
CANSAS–S (met need)					.214	.118	.147	.117
CANSAS–S (unmet need)					-.346	**.055**	.329	**.047***
BPRS					.133	.105	.193	**<.001***
HoNOS*			-.089	.493	-.021	.889	-.046	.662
CANSAS-P (met need)					.166	.423	-.0522	.744
CANSAS-P (unmet need)					.368	.182	-.0527	.794
Hospital admission					-.073	.974	-.764	.594
Recovery variables								
QPR							.083	.122
HHI							-.278	**.014***
MHCS							-.085	**.032***
MANSA							3.788	**<.001***
RFS-SU							1.799	**.017***

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 2)	p-value	Coefficient (Model 3)	p-value	Coefficient (Model 4)	p-value
WEMWBS							-.146	**.013***
INSPIRE Support							.006	.830
INSPIRE Relationships							.082	**.005***

Model fit was tested and compared across the models using three fit indices AIC, delta AIC, and likelihood and is shown in Table 8.7.

Table 8.7: AIC comparisons of the four models for the CSQ-8

Model Number	AIC	Delta AIC	Likelihood
1	638.92	414.12	0.00
2	287.44	62.64	0.00
3	281.12	56.35	0.00
4	224.80	0	1

For the CSQ-8, the fully saturated model was the best fit to the data as measured by the AIC and Delta AIC. The likelihood measure indicated that there was a less than 1% chance that Model 1 -3 were a better fit to the data compared to Model 4.

Interpretation of the multilevel mixed-effects linear regression analysis for the CSQ-8

The results of the CSQ-8 indicated that in three out of the four models (Models 2-4), when controlling for the effects of the included covariates, the intervention had a negative effect on satisfaction. The effect of the intervention ranged from reducing satisfaction by 2.4 points (Model 2) to 3.3 points (Model 4). Baseline CSQ-8 scores had a significant effect on end-point scores within all models. Within Model 4, which was the best fitting model, the intervention reduced satisfaction by 3.3 points. Significant predictors of the CSQ-8 scores at baseline within Model 4 were age, IQ, Gender, employment, relationship status, time in services, BPRS scores, service user-rated unmet need, hope, confidence, satisfaction with life, relationships with staff (as measured by INSPIRE Relationships), wellbeing and fidelity to the intervention.

The effect of the intervention on satisfaction was opposite to what was hypothesised. The results of the regression analysis were inconsistent with the mean values which indicated no significant difference in satisfaction between the intervention and control groups at endpoint (mean = 24.5 (4.5) and 24.4 (5.2) respectively). One explanation for this negative finding may be over-fitting of the regression model. Within regression analyses, increasing the number of covariates relative to the number of observations can inflate the coefficients and their related significance. In such cases where over-fitting occurs, the model explains random error and minor fluctuations in the data instead of true underlying effects. In an over-fitted model, the explanatory power of each variable will be low. To test this, the variance explained by the Intervention in Model 4 was calculated. The amount of variance explained by the intervention

variable was less than 1%. This suggested that the significant negative effect of the intervention on satisfaction was an artefact of model over-fitting. This was further tested in post-hoc sensitivity analyses presented in Section 8.2.4.

Secondary outcomes

As the AIC results indicated that Model 4 was the best fitting model, for the secondary outcomes, only Model 1 (unadjusted) and Model 4 (fully adjusted) were conducted. The results of the regression models for each secondary outcome are shown in Table 8.8. In each case, only the effect of the intervention on each secondary outcome is reported e.g. the HHI row indicates the effect the intervention had on the HHI endpoint scores within Model 1 and Model 4.

Table 8.8: Effect of the intervention on secondary outcomes (n=81)

Outcome	Coefficient (Model 1 - unadjusted)	p-value	Coefficient (Model 4 - fully adjust)	p-value
Service-user rated				
HHI	-.004	.997	.513	.893
MANSA	-.176	.458	-.671	**.004***
MHCS	-1.185	.734	-11.862	**<.001***
WEMWBS	-.620	.794	-5.337	**.003***
RFS-SU	.164	.284	.000	.995
ICECAP-A	-.032	.522	-.298	**<.001***
INSPIRE Support	2.019	.745	18.065	.322
INSPIRE Relationships	.125	.979	-.501	.897
CANSAS-P (met need)	1.407	**.053**	3.556	**.001***
CANSAS-P (unmet need)	.536	.499	1.653	.142
CANSAS-P (no need)	-1.416	.194	-5.208	**<.001***
Researcher-rated				
BPRS	1.142	.632	.639	.817
Staff-rated				
CANSAS-S (met need)	.238	.849	-.982	.463
CANSAS-S (unmet need)	-.301	.501	-.020	.974
CANSAS-S (no need)	-.402	.759	.384	.677
HoNOS*	-.409	.727	2.665	**.016***
GAF	4.798	.193	7.570	.169

Bold = p<0.1, *=p<.05

The results of the unadjusted regression model (Model 1) indicated that the intervention had no significant effects on any of the secondary outcomes, apart from service user-rated met need (CANSAS-P (met need)). The results indicated that individuals in the intervention arm rated their level of met needs higher than individuals in the control group. This significant

result was also apparent when other variables were controlled for in the fully adjusted model (Model 4).

Model 4 also indicated that the intervention had a significant and negative effect on mental health confidence (MHCS), subjective quality of life (MANSA and ICECAP-A) and wellbeing (WEMWBS), such that in all cases, individuals in the intervention group had lower ratings than the control group. The intervention was however associated with a positive effect on service user-rated levels of need, and a positive effect on staff-rated HoNOS. However, these findings may be due to over-fitting of the regression model (discussed in Section 8.2.4).

Assumptions of the multilevel mixed linear regression model.

As with any analysis, a number of assumptions were made about the data used in the multilevel mixed-effects regression models. These can be summarised as 1) linearity, 2) normality of residuals 3) homoscedasticity, 4) independence of the error terms, 5) variables are not multicollinear (predictor variables are significantly correlated) and 6) individual observations do not have a large influence on the estimates of the coefficient. These assumptions were tested.

Assumption 1 (linearity): The data validation checks, including the histograms and box plots indicated that this assumption was valid.

Although Assumption 2 (normality of residuals) to a certain extent was tested by the data validation checks assessing skewness and kurtosis, it was additionally tested by plotting the residuals. Residuals describe the difference between the predicted values (those predicted by the regression model) and the actual observed values [310]. Assumption 3 (homoscedasticity) and Assumption 4 (error terms) were also tested by plotting the residuals from the regression. For assumptions 2,3 and 4 to be met, the resulting scatter plot of the residuals against the predicted values should be randomly distributed in a rectangular shape, suggesting equal scatter around the mean.

The residuals of the best model (e.g. Model 4) were plotted to test the assumptions. The scatter plot of the residuals for the QPR is shown in Figure 8.2

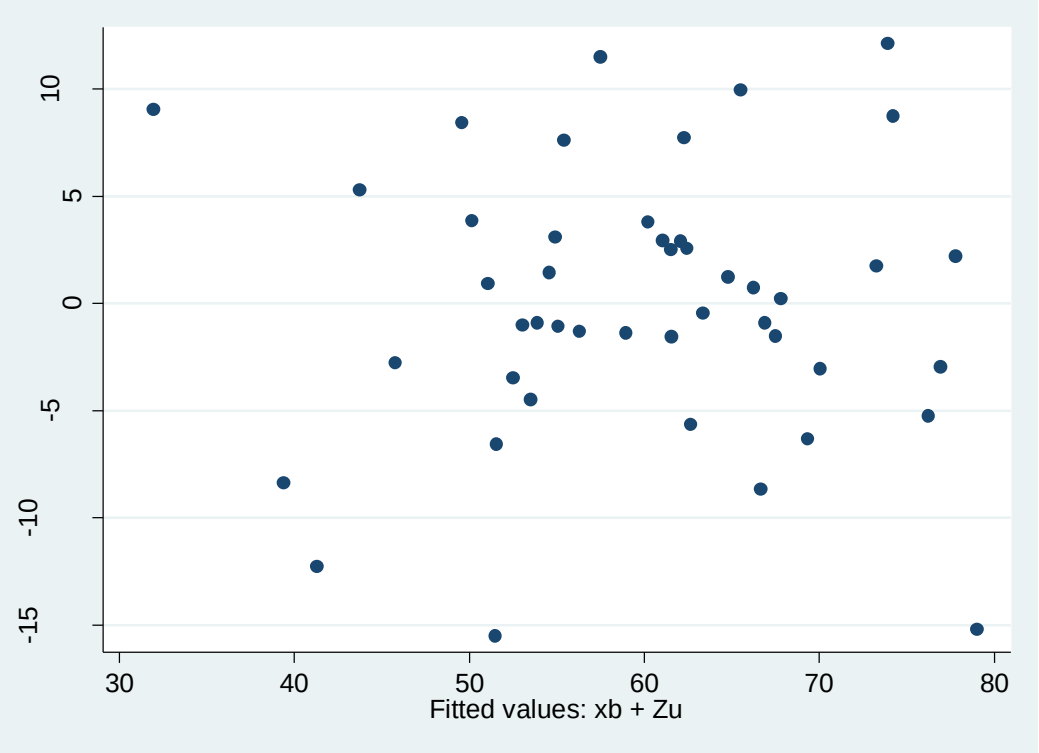


Figure 8.2: Level-1 plotted residuals QPR

The scatter plot indicated that assumptions 2, 3 and 4 were valid for the QPR, as there was a random distribution of plotted points. The scatter plot for the CSQ-8 is shown in Figure 8.3.

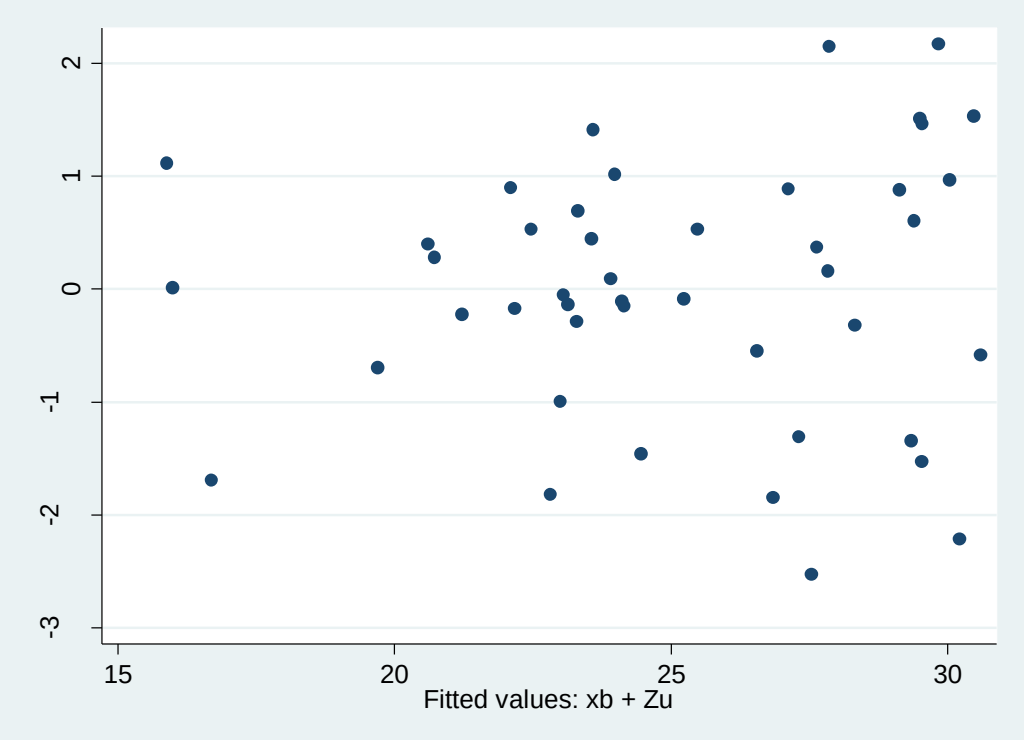


Figure 8.3: Level-1 plotted residuals for the CSQ-8

Again, the scatter plot indicated that assumptions 2, 3 and 4 were valid for the CSQ-8 as the distribution of points were random.

Assumption 5 (collinearity) was tested for all the primary and secondary outcome variables using the **collin** STATA command. The **collin** command provides the variance inflation factor (VIF). Tolerance, which is 1/VIF, is used to determine whether variables are collinear. A tolerance lower than 0.1 indicates that the variable is collinear and should be removed from the analysis. For all outcomes, the results varied from 0.11 to 0.34. This indicated that none of the outcome variables were significantly collinear indicating that assumption 5 was valid.

Finally, to check assumption 6 (influence of individual observations), the outliers identified in the data validation stage were excluded and the analysis re-run. The coefficients relating to the impact of the intervention on the two primary variables did not change as a result of removing the outliers (β =-3.79, p=.142 and β =-3.32, p=.001 for the QPR and CSQ-8 respectively). This indicated that assumption 6 was valid.

8.2.4 *A priori* sensitivity analyses

Strict ITT sample - multiple imputation models

To test the robustness of Model 4, sensitivity analyses were conducted. Although individuals within the main treatment effect analysis were analysed based on their allocation status regardless of whether they received the intervention or control (as per allocation), only individuals with complete data (after pro-rating) were included in the analysis. A strict ITT analysis aims to include all individuals as per allocation status, including those who dropped out of the study.

A sensitivity analysis was conducted to test whether using a strict ITT approach had an impact on the result. To achieve a strict-ITT sample, multiple imputation was used to compute values for any covariates or outcomes that were missing from the data set. As it is not deemed appropriate to impute data for individuals who have died, the participant in the control group who died during the study was excluded from the analysis.

The imputation model initially included all variables and covariates in the imputation model. However, evidence of collinearity between the CANSAS (service-user and staff-rated) scores, and the sociodemographic relationship status variable led to their removal from the final imputation model. The multilevel mixed-effects linear regression was conducted using the

imputed values and was compared to the non-imputed values. The fully adjusted (Model 4) and basic model (Model 1) were tested in the sensitivity analysis. The impact of all variables on the endpoint QPR scores are shown in Table 8.9.

Table 8.9: Regression co-efficients for QPR following multiple imputation (n=109)

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 4)	p-value
Intervention	1.56	.628	-1.314	.634
Baseline QPR			.746	**<.001***
Sociodemographic variables				
Age			-.061	.695
Borough			0.120	**.**471
IQ			0.849	.300
Gender			-2.537	.415
Employment			-2.262	.730
Education			-5.713	**.080**
Relationship status			2.258	.578
Accommodation			5.060	.096
Clinical variables				
Time in services			-.223	.169
CANSAS-P (met need)			.090	.794
CANSAS-P (unmet need)			.154	.777
BPRS			.048	.783
HoNOS*			-.246	.441
CANSAS-S (met need)			.577	.169
Hospital admission			-4.631	.389
GAF			.082	.488
Recovery variables				
CSQ-8			.083	.821
HHI			-.415	.264
MHCS			.184	.164
MANSA			1.065	.658
RFS-SU			-.790	.721
WEMWBS			-.098	.668
INSPIRE Support			-.004	.964
INSPIRE Relationship			.090	.375

Bold = p<.1 and *=p<.05

The results of the regression model following multiple imputation indicated that the intervention did not have a significant effect on QPR in either the adjusted or the unadjusted models. The only variable to have a significant impact on follow-up recovery scores were baseline recovery scores.

Table 8.10 presents the results of the strict ITT analysis using multiple imputation for the CSQ-8.

Table 8.10: Regression co-efficients for CSQ-8 following multiple imputation (n=109)

Measure	Coefficient (Model 1)	p-value	Coefficient (Model 4)	p-value
Intervention	.781	.626	-1.757	.251
Baseline CSQ			-0.040	.876
Sociodemographic variables				
Age			-.060	.437
Borough			-1.615	**.067**
IQ			.131	**.027***
Gender			2.193	.181
Employment			2.308	.481
Education			2.949	**.049***
Relationship status			2.751	.197
Accommodation			-.217	.900
Clinical variables				
Time in services			.029	.736
CANSAS-P (met need)			.024	.883
CANSAS-P (unmet need)			-.081	.761
BPRS			.201	**.035***
HoNOS*			.063	.714
CANSAS-S (met need)			-0.94	.624
GAF			.131	**.044***
Hospital admission			2.954	.290
Recovery variables				
QPR			.047	.662
HHI			-.127	.586
MHCS			-.032	.673
MANSA			.944	.495
RFS-SU			1.340	.239
WEMWBS			.064	.615
INSPIRE Support			-.051	.214
INSPIRE Relationships			.160	**.006***

Bold = p<.1 and *=p<.05

The results of the regression models for the CSQ-8 indicated that the intervention did not have a significant effect on satisfaction in either the unadjusted or adjusted model. This suggests that the significant effect of the intervention in the main analysis was a result of over-fitting the model with too many parameters relative to the number of participants. Multiple imputation increased the number of participants to 109. Three socio-demographic variables, namely borough, pre-morbid IQ and education had a significant impact on satisfaction as did researcher-rated symptom levels and the INSPIRE Relationships measure.

Post-hoc sensitivity analyses

Although the assumptions of the regression were valid, a second set of post-hoc analyses were conducted. In this post-hoc analysis, the unadjusted model (Model 1) and the fully saturated regression model (Model 4) were conducted as fixed-effects linear regression

models for both primary outcomes. These post-hoc analyses were conducted for two reasons. Firstly, the variance predicted by the above mixed-effects regression models was low (<40%). Secondly, the likelihood ratio test indicated that a mixed-effects regression model was not significantly better than a fixed-effects linear regression controlling for clustering at the team level (p=>.05).

In both post-hoc fixed-effects models, clustering was controlled for and robust standard errors calculated. In the unadjusted and fully adjusted models, the intervention did not have a significant impact on endpoint QPR scores. In the fully adjusted model, only QPR scores at baseline had a significant positive effect on end-point QPR scores (β =.80, p<.001).

In the fully adjusted model for the CSQ-8, baseline CSQ-8 scores were positively and significantly associated with endpoint (β =.501, p=.003). Baseline symptoms as rated by the BPRS (β=.170, p=.007), the INSPIRE Relationships measure at baseline (β=.097, p=.046) and gender (β= 4.90, p=.021) were all positively associated with end-point satisfaction scores. In contrast time in services was negatively associated with satisfaction at end-point (β= -.256, p=.0017). As with the multiple imputation models, both the unsaturated and fully saturated model indicated that the intervention did not have a significant effect on CSQ scores at endpoint. The fully saturated linear regression models explained 74% (QPR) and 86% (CSQ-8) of the variance in outcome.

The effect of the intervention on the secondary outcomes was also tested in this sensitivity analysis. In both the adjusted and unadjusted models, the intervention significantly increased the levels of service user rated met need (unadjusted β=1.419, p=.007; fully adjusted β= 3.556, p=.029). Additionally, within the fully adjusted models, the number of domains rated as no need by service users significantly increased (β= 5.208 p=.034). There were no significant intervention effects for the other secondary outcomes.

Summary of the quantitative analysis

The results of the both the *a priori* and *post-hoc* sensitivity analyses suggest the negative effect of the intervention on satisfaction was an artefact of over-fitting the regression model, with too many parameters relative to the number of observations. When using multiple imputation to increase the number of observations and when fitting a linear fixed-effects model, the negative effect of the intervention on satisfaction was no longer evident.

Furthermore, the fixed-effects models explained more of the variance in outcome than the mixed-effects models.

Overall the quantitative results indicate that the intervention did not have a significant effect on recovery or satisfaction at the end of the intervention. This finding did not support the two trial hypotheses under investigation. However, the intervention was associated with a positive increase in service user-rated level of met need. There was some weaker evidence to suggest that the intervention was also associated with a trend towards improved staff-rated levels of need (both met and unmet).

8.3 Qualitative analysis

The second objective was to understand the experience of the REFOCUS intervention, in particular in relation to Working Practice 1: Values and Treatment Preferences. The qualitative findings reported in this section relate to a sub-group analysis of black participants included in the wider process evaluation.

8.3.1 Participants characteristics

In total, eight individuals from a range of intervention teams were recruited into the process evaluation. Their characteristics are shown in Table 8.11.

Table 8.11: Process evaluation participant characteristics (n=8)

Characteristics	n=8
Gender (N, %):	
Female	1(12.5%)
Male	7(12.5%)
Age (Mean, SD)	36.9 (9.4)
Ethnicity (n, %):	
Black/ Black British - African	4(50%)
Black/ Black British - Caribbean	3(37.5%)
Mixed Black and White	1 (12.5%)
Diagnosis (n, %):	
Schizophrenia	2(25%)
Bipolar Disorder	1(12.5%)
Delusional disorder	1(12.5%)
Other	2(25%)
Did not want to disclose	2(25%)
Intervention Borough	
Lewisham (Wave 1)	4(50%)
Southwark (Wave 2)	2(25%)
Croydon (Wave 3)	2(25%)
Mental health team type (n, %):	
Support and recovery	6(75%)

Forensic	1(12.5%)
Low Intensity Team	1(12.5%)
Time in MH services years (mean, SD)	9.6 (4.8)

8.3.2 Coding framework

The 1st and 2nd order categories of the final coding framework are presented in Box 8-1

1st Order category	2nd Order category
1. Working Practices	1.1Understanding Values and Treatment Preferences
	1.2 Strengths assessment
	1.3 Goal setting
2. Working relationships which support recovery	2.1 Impact of REFOCUS on the working relationship
	2.2 Qualities of a recovery-supporting relationship
	2.3 Personal qualities of staff who support recovery
3. Impact of the REFOCUS intervention on personal recovery	3.1 Empowerment
	3.2 Identity
	3.3 Hope
4. Lack of noticeable change following REFOCUS intervention	4.1 Ineffective implementation of intervention
	4.2 Lack of noticeable change in the relationship
	4.3 Organisational barriers to change
	4.4 Societal barriers to recovery

Box 8-1: Process evaluation coding framework

Four main categories were included in the analysis and are now presented, with a particular focus on Working Practice 1: Understanding Values and Treatment Preferences. Within the following results, the 1st and 2nd order categories will be discussed, with the 3rd order categories for theme 1.1 Working Practice 1: Understanding Values and Treatment Preferences, additionally discussed.

Category 1: Working Practices

This theme described the experience of the different REFOCUS Working Practices. Suggested improvements for the Working Practices were also included in this theme. Participants gave rich descriptions and examples of the Working Practices, for example discussing the types of conversations they had had with staff, including the content of these new conversations. Participants also frequently discussed the impact of the three Working Practices on their overall recovery, and on specific components, such as identity or empowerment.

Category 1.1 Understanding Values and Treatment Preferences

Four subordinate categories were included in this theme. These were i) Examples of the VTP tools, ii) New topics of conversation with staff, iii)Impact of the VTP Working Practice and iv) Suggested improvements.

Examples of the VTP tools

Three approaches to learning about the values and treatment preferences of individuals were suggested in the intervention; conversational, narrative and visual. However, individuals only described experiencing the conversation approach to understanding values and treatment preferences. In particular, the conversational approach made use of the VTP Interview Guide. Throughout the interviews, participants talked about the discussions they had with staff around the areas included in the guide. Participants reported that the VTP Interview Guide encouraged new topics of conversation. In some cases, individuals worked though the guide together with staff and discussed the areas included.

> *"We talked about my recovery whether I'm making a good recovery or not and he said that I am making a good recovery I'm doing well. He asked me about my physical health, my mental health, social life, family life, spiritual life that sort of thing"* (PE4, Male Southwark).

No participant mentioned the two other approaches to understanding values and treatment preferences, although one participant did mention that his care coordinator had proposed using a visual map in a future meeting.

New topics of conversation

Participants discussed how the VTP Interview Guide led to new conversations with staff. This included discussions on sensitive areas not previously discussed. Participants reported feeling "*liberated"* when given the opportunity to discuss these areas with staff and noted the impact this had on their relationship as well as on their recovery.

> *"Well I just felt erm she is taking more interest in me, more than just coming and giving me injections, she wanted to know more about how I feel what I'm doing, what I'm thinking what am I feeling."* (PE3, Male, Lewisham)

Three areas in particular were mentioned as new topics of conversation. These were race, culture and ethnicity, sexuality, and spirituality.

One sensitive area that some individuals discussed with staff was race, culture and ethnicity. This included discussing the impact of racism and discrimination on the person's mental health and self-image. Although this area was not as frequently discussed as spirituality and sexuality, the conversations where they did occur were valued by service users. For some individuals this was an area that the person did not feel the need to discuss. Furthermore,

individuals saw the exploration of their values as a way to discuss areas that were particularly problematic or difficult for them at the time.

> *“Well it’s just um it’s like, I haven’t really thought about this, but yeah, it [referring to VPT guide] says describe your cultural identity, including those cultures and ethnicity, it talks about describing yourself, background, parents background, it’s alright it’s good but I’ve never had a problem with it"* (PE 7, Male, Southwark)

Although some participants did not feel it was appropriate to discuss sexuality with staff, for others, this was a new conversation that was welcomed. For one participant, it was during the REFOCUS intervention that they first discussed sexuality with their care coordinator. In this case, the discussion revolved around the impact on the person and their family.

> *"Yes she asked me about my sexuality and about being gay and that and the impact to my family life and as a whole"* (PE3, Male, Lewisham)

Conversations around spirituality and religion were also felt to be new. Individuals often stated this was an area not previously discussed with staff prior to the intervention, yet for many people it was an important part of their life.

> *"He asked how often do I go to Church? Do I enjoy it? Special connection with God and things like that……. he knows I’m a Christian so he just asks me questions related to my faith really, he says is my faith helping me?"* (PE4, Male, Southwark)

In addition to having these discussions, one participant mentioned how the conversation was reciprocal, with the staff member talking about their own spirituality. This was seen as a positive, which helped to build and strengthen the relationship.

> *"She's quite spiritual herself. So she can support me with my spirituality. You know. She'll just tell me to, you know, to pray and ask God for guidance, you know. Erm yeah, there's little things like that, you know, whatever I needed, top up a prayer or you know a church where I could feel comfortable because I was on the street before"* (PE1, Female, Lewisham)

1.1.3 Impact of the Values and Treatment preferences Working Practice

Where individuals had experienced discussions around their values and treatment preferences, overall they felt the impact was positive. This included the impact on their working relationship with staff, as well as the impact on their sense of self and personal recovery. Participants reported four benefits.

Impact 1: Staff were genuinely interested in the person

Having new conversations made participants feel that staff were interested in them, and wanted to get to know them as a person. Meetings with staff no longer fulfilled a clinical purpose, but instead covered areas in addition to mental health. Feeling that staff members were genuinely interested in turn made service users more likely to discuss other areas of their life. This included areas they had not previously discussed with their care coordinator.

> *"I just thought about coming to see her once a month to get my injection and leave, because we never use to talk but now that we've started talking I've started thinking about what she might ask me and what we can talk about."* (PE3, Male, Lewisham)

Impact 2: Helps to build a positive working relationship

Knowing more about the person led to increased mutual trust and respect between both individuals in the working relationship. Service users described how the relationship had benefited from staff members seeing and treating them as a person. The increase in mutual trust and feeling of genuine interest helped to build a more positive working relationship.

> *"She's looking at empowering me, which shows that she's interested in me as a person, I'm not just a statistic or just trying to move me on or just give me whatever help they've got and that's it. You know, she really cares, it really gives me a strong sense of how our relationship has improved markedly."* (PE1, Female, Lewisham)

Individuals also felt more positive towards the staff member when they perceived the person was taking a genuine interest in them.

> *"I felt a lot better towards her, as I felt she was more interested in me."* (PE4, Male, Southwark)

Impact 3: Understanding and seeing the person as an individual

The third benefit was the sense that staff members saw the service user as an individual, instead of just a diagnosis or a label. This included taking a whole-person approach to getting to know all about the individual.

> *"It made me feel that she's tried to know me, what's important to me, what was before. They talk to me and know me as a person.* (PE5, Male, Southwark)

Linked to understanding the person as an individual was a perceived reduction in assumptions made by staff. This was a particularly important theme included in the Framework of Recovery

Support and related to the implicit and sometimes explicit assumptions that are made in services about the type of care and treatment the person would want. These assumptions were often based on characteristics of the person, such as their skin colour or perceived culture. After discussing values and treatment preferences, participants reported that they were treated as individuals and that this sense of personhood was communicated through their interactions with staff.

> *"Ummm yeah I do, cause, they always make me feel that they know who I am and stuff like. They don't treat me like others, they talk to me and get to know me as a person."* (PE4, Male, Southwark)

Impact 4: Regaining a positive sense of self

The positive impacts of the Working Practice extended beyond the relationship with staff. Additionally, participants described the positive impact that exploring their own values and treatment preferences could have on their sense of self. In particular it gave people a sense of other areas of their life, and not just their mental health problems, with the VTP Interview Guide prompting greater self-exploration of identity.

> *I feel good talking about that… because she realised that I just, I don't really see myself as just having mental health problems, I've got another life as well, which is different, just different from this one here.* (PE2, Male, Southwark)

1.1.4 Suggested improvements to Working Practice 1

Although participants were on the whole positive about the experience of Working Practice 1, three suggestions for improvements were made.

Improvement 1: 'Asking for asking sake'

The first improvement related to the use of the information discussed, particularly the information shared about treatment preferences. Individuals wanted to ensure that any information shared was used in future care planning. As one participant stated, where the information was not used or taken forward, it felt as if staff were "*asking for asking sake*" (PE8, Male, Croydon).

Participants also suggested that staff needed to explain the reason for asking these questions, particularly where individuals had previously worked with the staff member for a number of years. Some individuals were more accustomed to conversations which focused on their difficulties. These individuals often felt that asking questions about areas of their life implied

that they had a problem in that area. This suggested that the way in which the intervention was introduced and delivered may need to be modified.

> *"Erm, I'm not sure to be honest, for me, it was a bit weird because I'd like to bring it up myself, I'm not saying I'm like, everyone else should, but I just, sometimes I like to bring it up myself rather than staff bringing it up."* (PE2, Male, Lewisham)

Improvement 2: Tick-box exercise

Some individuals commented that although they were happy to discuss the areas with staff, these discussions were not undertaken in an individualised manner. Instead, participants described how the VTP Interview Guide was used in an almost formulaic way. In these cases, participants described how staff members worked their way through the pre-defined set of questions, rather than tailoring the discussion to the person and their individuals needs.

> *"um I think actually, they just gave me that form saying um what, is important and, what would you like help you with and told me fill it in"* (PE4, Male, Southwark)

Individuals noted there was a need to have these conversations within the context of a recovery-supporting relationship. This meant ensuring any discussions or conversations around sensitive areas were service user-led and not just for the benefit of staff. Where the conversations weren't implemented in a recovery-orientated way, the experience could be negative.

> *"Mmm, um, (sigh) a bit depressed actually because I'm struggling trying to get it back and and get on with my life, so yeah, it's hard, I don't like talking about it."* (PE8, Male, Croydon)

Improvement 3: Use of VTP during first contact

The final suggestion within the interviews related to when the Working Practice could be used for maximum benefit to service users. Some participants suggested that the interview guide would be a good tool to use with all individuals upon their first admission or contact with services, further suggesting it could be used within early intervention services.

> *"I would have actually liked to have been asked at the beginning when I first came here, but the thing is they didn't ask you they just started treating you with drugs…it should be used early"* (PE1, Female, Lewisham)

The results will now briefly focus on the remainder of the coding framework shown in Box 8-1. This includes discussing the experience of the other two Working Practices before discussing the other categories included in the coding framework.

Category 1.2. Assessing strengths

The second Working Practice focused on assessing the strengths of service users and in particular, using the Strengths Assessment Worksheet with people. During the interviews, when service users gave examples of their strengths they focused particularly on valued personal qualities and less on external resources that were available to them. One of the positive impacts of the strengths assessment was that service users reported a greater awareness of their own strengths.

> *'It was good because it showed I've got a lot of courage, that's one of my strengths, I have a lot of courage'* (P6, Male, Croydon)

Where individuals had difficulty identifying their strengths, it was helpful to have staff encouragement. This included having staff members discuss their perceptions of the person's strengths. Although only apparent in a few examples, where discussions around strengths had been taken further to include planning how to utilise those strengths within the care plan, this was seen to be particularly useful and recovery-orientated.

> *'It makes me feel like it's something I can work with, something I can actually put into practice and make part of my routine. If I'm good at it and I want to do it, why shouldn't it be part of your routine?' (P2, Male, Lewisham)*

1.3 Supporting goal-striving

The aim of this Working Practice was for staff to work in partnership with the person in support of their personally valued goals. Compared to the other Working Practices i.e. assessing strengths and exploring values, service users were more familiar with goal striving, and often noted this as an area previously discussed with staff prior to the intervention. Goals gave people a sense of direction and purpose in life; something to '*aim for*'. Service users gave examples of personal goals, and how these had been shared with staff members or identified during discussions about goals.

> *'He'll ask me like what, because he knows I'm good at football so he knows that I'm going to always play football, he'll ask me what else I want to do with my life, where I see myself in say a couple of years or something like that and in terms of set targets' (P7, Male, Southwark)*

Service users found it particularly useful when staff worked collaboratively with them on the attainment of their goals. This included breaking goals down into manageable steps and helping with motivation. Identifying possible opportunities that could aid goal-striving was also valued. Whilst reaching a goal was reported to give a sense of achievement, the process of goal setting, whether they were ultimately reached or not, was also seen as helpful.

Category 2: Working relationships which support recovery

Some individuals described changes in their relationship with staff which could be clearly linked to the REFOCUS intervention. In these cases, there was either a marked change reported during the intervention period or elements of the intervention were explicitly mentioned. These examples were included in the theme "Impact of REFOCUS on the working relationship". Other individuals described many qualities of a working relationship which support recovery, but were unclear whether these qualities were due to REFOCUS or were apparent prior to the intervention. These qualities were included in the theme 'Qualities of a recovery supporting relationship'. The final subordinate theme focused on the 'Personal qualities of staff who support recovery'.

Category 2.1 Impact of REFOCUS on the working relationship

Some participants were able to discuss how the REFOCUS intervention changed their relationship with staff. In particular, individuals stated that the intervention enabled staff to learn more about the service user and view them as an individual with unique strengths and values. Participants explained that this helped to build mutual trust and respect in the relationship, with both parties '*warming*' to each other. An increase in service user-directed conversations was also reported, with individuals feeling able to actively contribute to the agenda of meetings.

> *"We've had really strong sessions where I've opened up and just been honest, with the way I'm feeling, so he knows about me more than most people, you know, that's the best way."* PE6, Male, Croydon)

Increased collaboration and a move towards a more balanced relationship where service users and staff were seen as equal partners were welcomed as recovery promoting and was apparent for some individuals during the intervention period.

> *"You respond more and you're more cooperative with the team because you feel that they value your opinion and it's important."* (PE1, Female, Lewisham)

Category 2.2 Qualities of a recovery-supporting relationship

Participants also discussed the qualities of a working relationship consistent with recovery principles. These qualities of the relationship were greatly appreciated and valued alongside clinical expertise and support. Participants valued staff communicating their belief in them and pointing out positive changes. This was welcomed as hope-inspiring and characterised a relationship which focused on the positive and less on deficits.

> "*They make me feel like I can believe in myself now.*" (PE7, Male, Southwark)

Some of the participants described a recovery-supporting relationship with staff which pre-dated the REFOCUS intervention. These relationships were characterised by involvement in decisions, goal setting, feeling listened to and respected as an individual. Where relationships already supported recovery, any changes brought about by the Working Practices may have been less distinct and harder for individuals to notice.

> *"I've always felt involved really from beginning to end (…) they always kept me involved, kept me abreast of what's happening, asked my opinion and took it on board."* (P4, Male, Southwark)

Category 2.3: Personal qualities of staff in a recovery-supporting relationship

Regardless of whether participants noticed any change during the intervention period, they frequently described the personal qualities of staff in a recovery-supporting relationship. This went beyond providing clinical care and included the personality, attitudes and values of staff. Participants also valued the ability of staff to be open and honest in a constructive but not dismissive way. This relied upon mutual trust between the staff member and service user.

> *"I've been out of work for a while now, about seven years I think. It's been a long time so he says it won't be easy but he still sees I've got a lot of strengths, a lot of positive things to contribute to an employer so he feels it's quite good, yeah." (P4, Male, Southwark)*

Category 3: Impact of the REFOCUS intervention on personal recovery

When individuals were asked about the impact of the REFOCUS Intervention, they often focused on the specific Working Practices. However, there was a large amount of overlap in the outcomes reported, with the outcomes mapping on to three of the recovery processes included in the Conceptual Framework (Chapter 3).

Category 3.1: Empowerment

Participants felt empowered by the intervention, both regarding their mental health and other areas of their life. Being given increased independence and choice in their care was indicative of staff belief in their capability to manage responsibility. This in turn made individuals feel more confident. Coupled with this was an increased confidence in their ability to overcome challenges and to manage other areas of their life.

> *"I found it quite liberating because they're asking me what I want, what I think is, you know, better for me… so I think it's given me a level of freedom and confidence because you feel that I can, I'm in a position where I can give you my opinion. So yeah, I do think it's empowering."* (P1, Female, Lewisham)

Category 3.2: Identity

The increased self-knowledge and more positive sense of self discussed in relation to Working Practice 1 was also a theme and outcome common to other areas of the intervention. In particular, the intervention led to the participant having a greater awareness of their strengths and available resources. This encouraged a more positive self-image.

> *"It does a lot for my morale I think, you know, it helps me to feel better about myself, that I'm, you know, that I'm moving on."* (PE5, Male, Southwark)

Category 3.3: Hope

Another important outcome for participants who experienced the intervention was the increased feelings of hopefulness. This was partly due to an increase in positive thinking and focusing on success, and partly due to staff members actively communicating their hope and belief in the person. Participants also reported an increased belief in the possibility of change.

> *"I feel more positive that I can go for what I said I was going to go for, and if someone else believes in me then I more believe in myself."* (PE7, Male, Southwark)

Category 4: Lack of noticeable change in experience of person using the service

Despite the positive experiences discussed above, some participants did not notice any change in their discussions or relationship with staff members during the intervention period. This category included four sub-themes.

Category 4.1: Ineffective implementation of the intervention

Although participants could describe values, strengths and goals-setting, many participants could not recall having experienced the intervention, even when prompted. This may suggest

that the intervention was not (fully) implemented by staff. Furthermore, participants described incidences where the intervention was implemented, but the way in which it was delivered was ineffective. For instance, some individuals saw the Working Practices as another form that needed to be completed for the benefit of staff members. In these cases, participants felt that the Working Practices were not used in an individualised manner. Where the intervention components were delivered in this way, they were not seen as positive, with one participant describing a negative experience of the intervention.

> *"Maybe my Mum will come in and things like that, there's things I don't want to discuss in front of my Mum and everything erm, there might be erm, maybe some religion or spirituality or erm, or sexuality and things like that, erm, it makes me feel a bit embarrassed."* (PE2, Male, Lewisham)

Some even felt that the areas covered were intrusive, and did not want to discuss wider aspects of their life and even questioned the '*agenda*' of staff.

Category 4.2: Lack of noticeable change in the relationship with staff

Some participants stated that their relationships with staff during the REFOCUS intervention remained the same, particularly with regards to the power relationships. For these individuals, the relationship did not become any more recovery-orientated. Participants described how the decision-making power remained with staff, with differences in opinion seen as evidence of pathology, and medication remaining the focus of interactions. It was the perception of some individuals that staff did not want the working relationship to change.

> *"I don't think that words ever been mentioned, recovery. They just said um doing okay, compliant with medication, no drink or drugs or anything antisocial."* (PE8, Male, Croydon)

Further to this, some individuals, especially those who had been using the service for a long time, did not want their relationship with staff to change. Some individuals sought to have minimal involvement with services and were not receptive to broadening the role of services beyond risk and medication management. Others had negative experiences of mental health services for many years and couldn't imagine it being different. This indicated a need for raising the expectations of service users relating to services.

> *"I don't think I've ever made a decision about my care, I don't know what kind of decision I would make about my care."* (PE3, Male, Lewisham)

Category 4.3: Organisational barriers to change

Challenges at an organisational level were identified. Participants spoke about not having access to services that could meet their recovery needs. For some this was about help they wanted, for example psychotherapy or vocational support, not being available.

Non-continuity of staff was another important organisational barrier to recovery. Participants reported that building mutual trust and understanding took time and effort on both parts. This was often *'lost'* by sudden changes of staff involved in their care.

> *"What scares me is that they'll change him and put someone else new…and I'll have to do it all over again (…) Just a waste of good time (…) I still feel nervous, cos, I'm just waiting for a day when they say "here's your new care coordinator".* (PE6, Male, Croydon)

Category 4.4: Societal barriers to recovery

Consistent with the participants interviewed for the Framework of Recovery Support, individuals in the process evaluation described facing barriers within society which made recovery more difficult. Predominantly these societal barriers focused on the difficult experiences within the individual's personal life, for example abuse and bereavement, and experiences of stigma and discrimination.

> *"I think people in society have an attitude towards mental health because a lot of people as I said they - the stigma's created by ignorance and I think we need to be opened up and out in society."* (PE1, Female, Lewisham)

8.3.3 Summary of process evaluation findings

The process evaluation indicated that where individuals described receiving the REFOCUS Intervention, it was associated with positive effects. The VTP Interview guide was associated with new topics of discussion with staff. This led to individuals feeling that staff were genuinely interested in getting to know them as people. Additionally the VTP Interview Guide helped individuals to learn about their own values and assisted in the development of a more positive sense of self. The other Working Practices within the intervention were associated with hope, empowerment and increased knowledge of personal strengths and resources.

Individuals described the qualities of a recovery-supporting relationship. This included having staff who were genuinely caring and hope-inspiring, yet open and honest with the person. However, participants were less clear whether this was a direct result of the intervention, with

many people describing recovery-supporting relationships which predated REFOCUS. Where service users failed to notice any changes, this may have been due to the intervention not being implemented or implemented ineffectively. Alternatively the intervention may not have been noticeable to service users.

8.3.4 Reflexivity

I was mindful throughout the interviews that being part of the research team, and in particular being involved in the development of the intervention may bias the data collection. During the interviews I made sure the participants directed the conversation as much as possible, with individuals given time to talk about their rich experiences of services over the previous year. I would start the interviews with general questions to see if the service user raised anything about the intervention. I would only probe about the intervention content when service users indicated that they had either covered the included areas (such as strengths, goals, values) or had explicitly talked about changes in the relationship.

To overcome the impact of my previous knowledge of the intervention on the data analysis, a second coder independently coded transcripts. The second coder was from a lived experience background and had not been involved in the development of the intervention. During coding we met regularly to discuss the developing coding framework and used memos to record any instances where our interpretations of the data were different.

8.4 Integration of Qualitative and Quantitative analysis

The third objective of the trial was to integrate the quantitative and qualitative data to validate the Framework of Recovery Support developed in Chapter 5. To achieve this objective, data from the process evaluation were integrated with the quantitative findings of the trial to test a pathway included in the Framework. Structural Equation Modelling (SEM) was used to integrate the two types of data, the results of which are now presented.

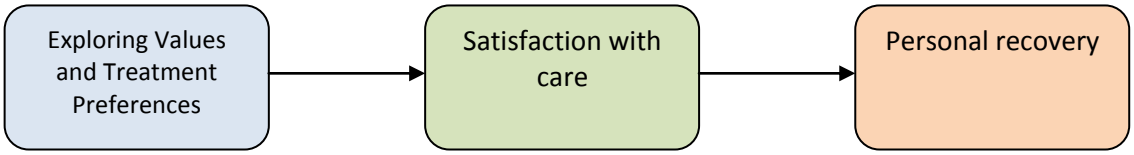
8.4.1 SEM using qualitative themes to identify latent constructs

To integrate the quantitative and qualitative data, an exploratory analysis was conducted. The themes apparent in the qualitative data were used to identify important concepts to be included in the SEM analysis. The qualitative data suggested that where individuals explored their values and treatment preferences (regardless of being part of the intervention or not), this was associated with increased satisfaction with the working relationship with staff and higher ratings of personal recovery.

The path between the concepts tested in the SEM was based on the Framework of Recovery Support. The Framework of Recovery Support suggested that increased experience of the values and treatment preferences Working Practice would lead to increased satisfaction with care and increased recovery. However, it should be noted that although the path tested was suggested by the Framework of Recovery Support, the results of the SEM show only association and not causation. Therefore it is possible that alterative paths and interpretations may exist. For example, improved recovery could have a direct effect on satisfaction.

Quantitative trial data were used to measure each of the concepts in the SEM analysis. To measure recovery, a latent variable consisting of the mean of the two QPR sub-scales was used. The mean CSQ-8 score was used to measure satisfaction with care, and the RFS-SU item: "Have staff asked you about the things that are important to you and your treatment preferences" was used as the measure of exploring values and treatment preferences (VTP).

Two SEM models were developed. Model 1 tested whether the experience of the VTP had a direct effect on satisfaction with care, and whether satisfaction with care had a direct effect on personal recovery. Model 1 also included an indirect effect of exploring values and treatment preferences on personal recovery. The path tested in Model 1 is shown in Figure 8.4.



Model 1

Figure 8.4: SEM Model 1

Model 2 additionally tested whether exploring values and treatment preferences had a direct effect on personal recovery, in addition to the indirect effect, and the direct effect on satisfaction with care. Model 2 is shown in Figure 8.5.

Model 2

Figure 8.5: SEM Model 2

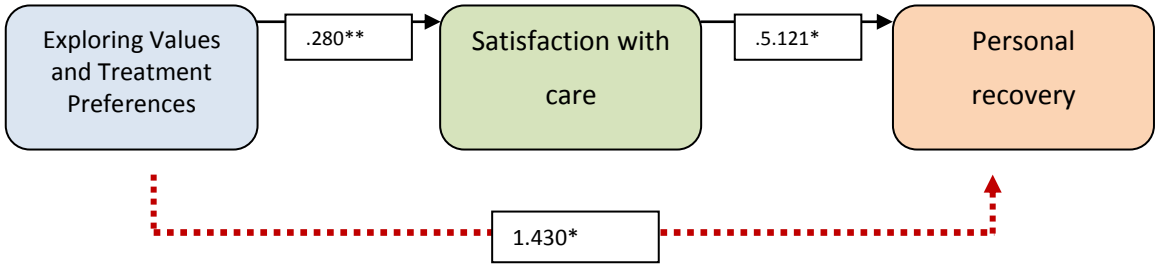
As the process evaluation indicated that many individuals had previously experienced exploring their values and treatment preferences with staff, within the SEM analysis, the whole sample was used regardless of intervention allocation. This was confirmed by the results of the SEM analysis which indicated that there were no significant differences in the regression coefficients between the control and intervention groups. Therefore the results are presented for the whole sample.

Table 8.12 shows the standardised and unstandardised regression coefficients for each of the variables included within Model 1. The table also presents the critical ratios and p-values.

Table 8.12: Regression coefficients for SEM Model 1

Regression model	Unstandardised coefficient	Standardised coefficient	Critical Ratios	p-value
Exploring VTP → Satisfaction	.280	.352	4.43	<.001
Satisfaction → Recovery	5.121	.405	2.98	.002

This is shown diagrammatically in Figure 8.6. Within the diagram direct effects are shown as solid lines and indirect effects as a red dotted line.



** p<.001, *p<.05

Figure 8.6: SEM results for Model 1

As shown in Figure 8.6 exploration of values and treatment preferences had a direct and significant effect on satisfaction, although the effect was small. For every 1 point change in the RFS-SU (range 1 to 3), satisfaction as measured by the CSQ-8 (range 8-32) increased by.28. Satisfaction had a direct and significant effect on recovery, such that for every point increase in satisfaction there was a 5.12 increase in QPR scores (range 0 to 88). The indirect effect of exploring values and treatment preferences on recovery indicated that for every one point increase in RFS-SU item 2, there was a 1.43 increase in QPR scores. The Sobel test confirmed that this indirect effect was statistically significant (Sobel test statistic = 2.477, p =.007). Overall, all hypothesised pathways were supported.

Within the model, Exploring VTP explained 12.4% of the variance of satisfaction scores, whereas satisfaction explained 16.4% of the variance of recovery scores. The critical ratios for both direct effects, i.e. exploration of values and treatment preferences on satisfaction and satisfaction on recovery, were above the 1.96 value suggesting both were important factors and should be retained in the model (critical ratio = 4.43 and 2.98 respectively).

Model fit was tested using Chi^2 goodness of fit test, Comparative fit index (CFI) and Root mean square residual (RMR). The results of the model fit tests are shown in Table 8.13

Table 8.13: Model fit tests for Model 1

Model Number	Chi^2 goodness of fit test	Comparative fit index (CFI)	Root mean square residual (RMR)
Model 1	X^2=8.2, p=.042	.917	.126

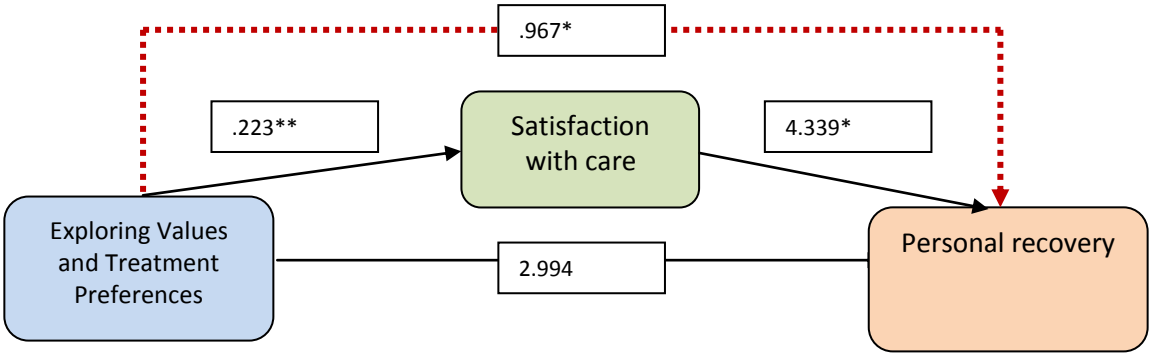
Model 1 produced adequate results for all model fit tests apart from the Chi^2 goodness of fit test, which was significant. This significant results suggests that the values (covariate matrix) predicted by the model differed significantly from the observed values in the data.

Table 8.14 shows the standardised and unstandardised regression coefficients for each of the variables included within Model 2. The table also presents the critical ratios and p-values.

Table 8.14: Regression coefficients for SEM Model 2

Regression model	Unstandardised coefficient	Standardised coefficient	Critical Ratios	p-value
Exploring VTP → Satisfaction	0.223	.284	3.92	<.001
Exploring VTP + Satisfaction → Recovery:				
Exploring VPT	2.994	.265	1.64	.101
Satisfaction	4.339	.302	2.44	.015

This information is presented diagrammatically in Figure 8.7. Within the diagram direct effects are shown as solid lines and the indirect effect as a dotted red line.



** p<.001, *p<.05

Figure 8.7: SEM results for Model 2

As shown in Figure 8.7, the direct effect of exploration of VTP on satisfaction remained significant. For every one point increase in the RFS-SU, there was a 0.22 increase in CSQ-8 scores. There was also a significant direct effect of satisfaction on recovery, whereby for every one point increase in CSQ-8, there was a 4.34 increase in QPR scores. Model 2 also included a direct effect of exploring values and treatment preferences on recovery. The unstandardised regression coefficient indicated that for every one point change in RFS-SU item 2 there was a 2.99 change in recovery as measured by the QPR. This was approaching statistical significance.

Model 2 also included an indirect effect of exploring values and treatment preference on recovery. For every one point increase in the RFS-SU, there was an indirect increase of .97 on QPR scores. The Sobel test indicated that this indirect effect was statistically significant (Sobel's test statistic = 2.07, p=.019).

Within Model 2, exploring VTP explained 8.1% of the variance associated with the satisfaction scores, whereas exploring VPT and satisfaction combined explained 20.7% of the variance associated with recovery scores. The critical ratios for exploring VTP on satisfaction and satisfaction on recovery were above 1.96 indicating they were important factors to the model (3.92 and 2.44 respectively). The critical ratio for the direct effect of exploring VTP on recovery was slightly below the significant 1.96 value at 1.64.

The results of the model fit tests for Model 2 are shown in Table 8.15.

Table 8.15: Model fit tests for Model 2

Model Number	Chi^2 goodness of fit test	Comparative fit index (CFI)	Root mean square residual (RMR)
Model 2	X^2=5.3, p=.069	.947	.124

Model 2 produced adequate results for all model fit tests. Unlike, Model 1, the Chi^2 value was not significant. This finding suggests that the predicted values of the covariance matrix did not significantly differ from the observed values and hence the model is a good fit to the data.

Assessing which model was the best fit

As Model 1 was nested within Model 2, AIC values could be used to compare the fit of each model. The AIC values indicated that Model 2 was the best fit for the data (Model 1 AIC = 30.21 , Model 2 AIC =29.34).

Summary of the SEM analysis

The results suggested that Model 2 was the best fit to the data. Within Model 2 there was a direct and positive effect of exploring values and treatment preferences on satisfaction, a direct and indirect positive effect on recovery, and a direct positive effect of satisfaction on recovery. This suggests that increased exploration of identity is linked to improved satisfaction with services and increased subjective ratings of personal recovery. Furthermore, the model suggests there is a positive link between increased service satisfaction and recovery. These findings are consistent with that path predicted by the Framework of Recovery Support.

Chapter 9 Discussion

This chapter discusses the findings of the thesis. A summary of the main findings for each of the three aims of the thesis is presented in Section 9.1. This is followed by an in-depth discussion of the findings of the cluster RCT in Section 9.2. The strengths and limitations of the trial and thesis are then presented (Section 9.3). The clinical and research implications of the thesis are discussed in Section 9.4, with reference to the wider literature on the mental health needs and experience of black individuals.

9.1 Summary of the main findings

The research question addressed by this thesis concerned how to support the recovery of black individuals who use community mental health services. To answer this question, three aims were included in the thesis. These were i) To develop a Framework of Recovery Support ii) To use the framework to develop a component of the REFOCUS Intervention and iii) To test the effectiveness of the REFOCUS Intervention for individuals from black communities.

Aim 1 (framework development) was met through a systematic review and narrative synthesis of the existing recovery literature, and by a new qualitative study. The review included an *a priori* subgroup analysis of papers focusing on the meaning of recovery for people from non-majority populations. The Conceptual Framework of Recovery was developed from the review and subsequently published [110]. The Conceptual Framework identified five key recovery processes: Connectedness, Hope and optimism, Identity, Meaning and Purpose and Empowerment (CHIME). The sub-group analysis of non-majority papers identified five areas of difference in the meaning of recovery for non-majority populations: Spirituality and religion; Stigma and discrimination; Culturally specific facilitating factors; Mental health system level barriers; and Individualistic vs. Collectivist values.

To develop the Framework of Recovery Support, 14 individual interviews and four focus groups were conducted. Regaining a positive sense of identity was identified as the core category. Individuals described experiencing multiple threats to their identity which included the impact of mental illness, and being a black individual within society. The effects of racial and ethnic discrimination meant that individuals felt they belonged to multiple stigmatised backgrounds. Part of the recovery process was moving from this negative sense of self to a more positive identity. The framework identified that recovery could mean different things to different people which was on a continuum from returning to the same person as before the

illness to becoming a new person. Facilitators of regaining a positive sense of self were also identified.

Aim 2 (intervention development) was met by developing a component of the REFOCUS Intervention, Model and Manual. The Framework of Recovery Support was used alongside the Conceptual Framework to identify underlying recovery principles which guided the development of the intervention. The REFOCUS Intervention included two main components: i) Recovery-Promoting Relationships, and ii) Working Practices. Three Working Practices were included: 1) Understanding Values and Treatment Preferences, 2) Assessing service user strengths and 3) Goal striving. Working Practice 1: Understanding Values and Treatment Preferences was the component developed as part of this thesis. This component focused on the exploration of identity and the impact that different values can have on a person's treatment preferences.

The REFOCUS Model was based on the Theory of Planned Behaviour [282] and specified the anticipated effects of the intervention as well as the underlying change processes. The REFOCUS Manual included details of the REFOCUS Intervention, the REFOCUS Model and additionally included the implementation strategies used within the trial.

Aim 3 (intervention evaluation) was met by assessing the effectiveness of the REFOCUS intervention for black individuals using community mental health services in an RCT. The cluster RCT had three objectives: i) to test the effectiveness of the intervention (quantitative); ii) to understand the experience of the intervention (qualitative); and iii) to integrate the two types of data to validate the Framework of Recovery Support. Two hypotheses were tested in the cluster RCT: that the intervention would lead to significant improvements in personal recovery (Hypothesis 1) and satisfaction with services (Hypothesis 2) as compared to standard care. One hundred and ten individuals were included in the trial. The results indicated that the intervention had no effect on either primary outcome. There was some evidence for positive effects of the intervention on service user-rated levels of met need, and some weak evidence for improvements in staff-rated levels of need.

The findings relating to aims 1 and 2 were previously discussed in Chapters 3, 5 and 6. The results of the cluster RCT which addressed aim 3 are now discussed.

9.2 Discussion of the REFOCUS RCT

9.2.1 Main treatment effect

One hundred and ten individuals were included in the trial with 81 followed-up after one year. This represents a follow-up rate of (73.6%). The follow-up rate within the trial was consistent with other studies recruiting individuals with severe mental health problems, including psychosis. For example, a review of trials assessing the effectiveness and implementation of illness management and recovery (IMR) reported that attrition rates varied from 18-38% [193]. Within the UK, two intervention studies, one assessing a psychosocial intervention [224] and the other a service-level intervention [311] reported follow-up rates of 66% and 75% respectively. Both of these previous studies were conducted with black individuals who used community mental health services. Meta-analytic evidence from a Cochrane review of CBT studies, suggest follow-up rates of around 70% in the studies included in the review [312]. This suggests that overall, the REFOCUS intervention and RCT was as acceptable to service users as the other interventions described.

The results of the analysis of treatment effect indicated that the intervention had no effect on either primary outcome (QPR and CSQ-8). Although the mix-effects regression modelling initially indicated that the intervention had a negative effect on service satisfaction, planned and post-hoc sensitivity analyses suggested this was due to model over-fitting (discussed as a limitation in Section 9.3.2). Consequently, the results did not support the hypotheses under investigation, and instead the null hypotheses - that the intervention will have no effect on i) recovery or ii) satisfaction – were supported.

The effect of the intervention on a range of secondary outcomes measured at end-point was also tested. The analysis indicated that the intervention was associated with positive effects on service user-rated levels of met need (CANSAS-P). These findings indicated that service users in the intervention arm rated more of their needs as met compared to those in the control arm. This finding was supported by the sensitivity analyses. There was also some that the intervention was associated with positive changes in the level of need as rated by staff. There was no effect on any of the other secondary outcomes, including recovery outcomes such as hope or quality of life.

9.2.2 Process evaluation findings

To understand the processes occurring within the intervention, including the level of implementation and the experience of participants receiving the intervention, a qualitative

process evaluation was conducted as part of the cluster RCT. Overall the process evaluation indicated that the intervention, where noticed by service users, was experienced positively, such that it facilitated a working relationship between staff and service users characterised by increased mutual openness and trust. The Working Practices led to a greater awareness of the person's strengths and values.

However, individuals were not always sure that the positive experiences around values, treatment preferences, strengths and goals were a direct result of the intervention, rather than being pre-existing features of their routine care. Some participants struggled to notice any changes during the intervention period. Where individuals did not experience any change it was often unclear whether the intervention was not implemented by staff, or whether the intervention was implemented but not noticed by service users.

9.2.3 Integrating the qualitative and quantitative results

The final objective of the cluster RCT was met by an exploratory SEM analysis. Within the analysis, exploration of identity was significantly and positively associated with increases in both service satisfaction and personal recovery.

9.2.4 Explanation of the cluster RCT findings

The findings did not support either trial hypothesis, and were inconsistent with the REFOCUS Model (Chapter 6). There are at least six reasons why the intervention may have had no effect.

Firstly, the results of the trial may suggest that the REFOCUS intervention is ineffective in its primary aim of improving personal recovery or may not be effective within the limited time frame of the intervention. Although shorter than the present intervention, similar findings were reported in a study assessing a peer-based culturally adapted intervention [201]. Within the study, individuals reported that the six month time period was not sufficient to form strong and trusting relationships with staff [201]. Relationships were one of two components within the REFOCUS Intervention. Furthermore many individuals in the REFOCUS trial had been using services for a long time, and may have already established long-term relationships with staff. Consequently, any changes to an individual's personal recovery and the relationship with staff within only a year may have been too subtle to detect. This explanation is partly consistent with the REFOCUS Model which included recovery as a distal outcome, with other recovery processes such as hope and empowerment included as proximal

outcomes. However, the results of the trial also indicated that the intervention had no effect on these proximal outcomes.

The second explanation for the lack of effect is inadequate implementation. Although not reported in the present thesis, fidelity and implementation data from the staff perspective were collected as part of the wider REFOCUS trial and have since been published [313]. Findings from the staff process evaluation suggest the intervention was poorly implemented, with barriers at the individual, team and organisation level. This is consistent with other pragmatic trials, particularly those assessing complex interventions within healthcare settings [314,315]. For example, Hall and colleagues assessed implementation within a cluster RCT of electronic outcome measurement in routine mental health practice. Their qualitative process evaluation indicated that it was difficult to engage clinicians in training, particularly where training was not mandatory [314]. Consistent with this finding, the training component of the REFOCUS Intervention was not mandatory within SLaM but relied on the engagement of the clinical team.

The low level implementation of the intervention is consistent with the findings of a recent Cochrane review which assessed the implementation of treatment guidelines within specialist mental health care. The review highlighted that the evidence for guideline implementation within standard care was poor [316]. Tansella and Thornicroft have highlighted how implementation of evidence into practice can be faced with many *'translational roadblocks'* [[317] p283]. They differentiate three implementation stages: adoption in principle, early implementation, and persistence of implementation. Although policy now supports the implementation of a recovery-orientation, including approaches such as that advocated within REFOCUS, this represents adoption in principle, and may not lead to implementation within practice [317].

Furthermore, although feasibility was one criterion used to determine inclusion within the intervention and manual, feasibility of an intervention is only one factor important to the implementation of an intervention within practice. Within their Consolidating Framework For Implementation Research, Damschroder and colleagues propose five domains [257]. These are i) intervention characteristics, ii) outer setting, iii) inner setting, iv) characteristics of the individuals involved and v) the process of implementation. Within the present thesis, only the intervention characteristics were considered within the REFOCUS Intervention and Manual. Future work will need to focus on implementation of a recovery intervention from both a

bottom-up and top-down perspective, with implementation strategies addressing all areas of the Consolidating framework [257].

The third reason, which is linked to the above, may be due to ineffective implementation. This would suggest that the way the intervention was delivered was not consistent with the manual and underlying recovery principles. The findings from the process evaluation provided some support for this explanation. Individuals within the process evaluation explained how in some cases the Working Practices were used in a formulaic way, with staff members deciding what areas to discuss. Furthermore, individuals described how the intervention was used as a tick-box exercise. When ineffectively implemented in this way, elements of the intervention were experienced as intrusive and for the benefit of staff. This finding is consistent with the results of a previous study conducted within SLaM [318]. The RETRAIN study involved delivering recovery training to staff working within CMHTs. Findings from the mixed methods study indicated that many staff members framed recovery as something over which they had ownership, and where there was a need to engage service users in order to *'do recovery to them'* [318].

A fourth explanation is that staff were already doing the elements of the intervention within their practice. Consequently, the REFOCUS intervention may not have represented a new way of working. This suggestion is consistent with the increased emphasis on recovery within mental health services [178]. Furthermore, as mentioned above, some teams included within the trial had previously taken part in the RETRAIN study which included the provision of team-based recovery training [318]. This explanation is partly consistent with the results of the exploratory SEM analysis which demonstrated positive effects of exploring values and treatment preferences on both satisfaction and personal recovery across the whole sample. Individuals often failed to identify that the conversations about strengths, values and goals were new and/ or due to the intervention. However, this is inconsistent with other research suggesting the need to increase the recovery-orientation of mental health teams [178]. Indeed, Roberts and Boardman noted that one of the top concerns with recovery for staff was the notion that most people felt they were already "doing recovery" [116,172].

The fifth reason for lack of effect relates to the measures used within the trial. There was some evidence of ceiling effects for the CSQ-8 (section 8.2.2). Ceiling effects reduce the sensitivity to change and hence the chance of detecting positive changes due to an intervention [319]. One explanation for the observed ceiling effects is that the pre-

intervention characteristics of participants may determine outcome measurement, including satisfaction [320,321]. This was consistent with the analysis which indicated that the only robust predictor of endpoint satisfaction was baseline satisfaction.

Linked to this explanation and the pre-existing characteristics of participants is the concern of sample representativeness. In order to recruit individuals for the trial, staff members within the trial teams mediated access to potential participants and determined eligibility. Within the literature, there have been reports of "gate-keeping" by staff members [322,323]. Research has indicated that staff members may be reluctant for individuals to take part in research for a range of reasons which has an impact on the pool of potential participants to whom the researchers have access to [323,324]. Clinical characteristics of potential participants have been shown to be one factor clinicians consider, with individuals who are more stable and engaged with the service more likely to be put forward by the clinician for research [323,324].

This suggestion of recruitment bias is supported by the overall percentage of individuals randomised compared to the number assessed for inclusion. Despite the primarily pragmatic nature of the trial, such that the intervention was delivered in routine practice, only 30% of black individuals on the caseload who were assessed for inclusion in the trial were subsequently randomised. As shown by the CONSORT diagram in Figure 8.1, 42% of those assessed for eligibility were deemed by staff not to be eligible for inclusion. Furthermore, 28% of participants refused to take part.

In addition to the issue of staff 'gate-keeping' as discussed, the refusal rate may also relate to the randomised nature of the study. Although not specific to black individuals, Sumner and Colleagues investigated willingness to participate in psychological intervention trials amongst a sample of individuals with psychosis. The study indicated that although the majority of individuals (90% of the sample) were willing to participate within a trial, people preferred not to be randomised, particularly to treatment as usual [325]. This may suggest that randomisation and a treatment as usual arm of a trial (rather than an active comparator) may be barriers to participation for some individuals.

However, despite these concerns, the consent rate of those deemed eligible to participant which was observed within the present study is comparable to other interventions studies conducted with individuals with psychosis. For example, the consent rate within an RCT study of culturally adapted CBT for psychosis was 32% of the sample assessed for eligibility, with

47% of eligible individuals refusing to participate [226]. The eligibility and opt-in rates for the present thesis are also comparable with other cluster RCTs. For example, a cluster RCT of vocational rehabilitation for young people with psychosis which was conducted within the same area of London as the REFOCUS study, found that 55% of the case load assessed were not eligible to participate, with a further 50% of those eligible refusing to participate [326].

The sixth explanation for the lack of effect in the cluster RCT may be due to the pragmatic nature of the trial. Although the trial applied eligibility criteria and included some level of involvement from the research team in order to deliver the intervention, the intervention was implemented within routine care [286]. Ruggeri and colleagues note that it is not easy to distinguish pragmatic and explanatory trials and have suggested the need for a new range of hybrid trials which include elements that are pragmatic as well as elements that are explanatory[321]. One of the features of a pragmatic trial is in the routine implementation of the intervention, which increases the external validity of the results [286,321,327]. However, this means that participants within the study also have access to a range of treatments in addition to the intervention under investigation. Although this makes the results more applicable to routine practice, unequal access to treatments across different arms of the trial may mask intervention effects. It is possible that within the REFOCUS Trial, as randomisation was at the team level, there may have been differences in the services and interventions available to individuals within each team, which masked any treatment effect.

In addition to the primary outcomes, the analysis also assessed the impact of the intervention on a range of secondary outcomes. The results indicated that the intervention was only associated with positive changes in both service user and staff-rated level of need. One possible reason for the improvement in met needs may be due to the Working Practices. One possibility is that by helping service users to identify their strengths and resources, staff members are assisting service users to meet their needs. However interpretation of these secondary outcomes is difficult. Wiersma and colleagues have questioned the use of needs as an outcome measure within trials. Their study indicated that although sensitive to change, levels of unmet need tended to significantly decrease with time in both the intervention and the control group [328]. Furthermore, the agreement between staff and service user-rated levels of needs was low. This resulted in the suggestion that levels of need may not be suitable for as an outcome for treatment evaluation.

9.2.5 Comparison of REFOCUS to other interventions for people with psychosis

The development and evaluation of the REFOCUS Intervention can be compared to other interventions for people with psychosis. These include recovery-orientated, and psychosocial interventions.

Recovery Interventions

As reviewed in Chapter 4, a number of interventions to support recovery have an emerging empirical evidence base. In particular, two approaches to self-management reviewed in Chapter 4, namely, WRAP and IMR, have RCT evidence for their effectiveness. A range of positive outcomes have been demonstrated for both IMR and WRAP. These include improvements in quality of life, reduced symptom levels as well as increases in hope and empowerment [182,183,184,185]. These studies have included a range of participants, including individuals with SMI and psychosis, as well as depression and anxiety [193].

Although not demonstrated within the quantitative analysis, which failed to find any significant effects of the REFOCUS Intervention on hope and empowerment, the profile of effects demonstrated for both WRAP and IMR are consistent with the process evaluation findings. Within the process evaluation participants particularly mentioned how the intervention led to increases in hopefulness, and made them feel more empowered. Furthermore as highlighted in Section 9.2.1, the acceptability of the interventions as measured by the attrition rates was similar for REFOCUS compared to both WRAP and IMR.

However, despite this overlap in positive findings, both IMR and WRAP have been delivered and tested as discrete interventions. This difference in delivery has implications for the feasibility of an intervention, including the resources required to deliver the intervention and complexity of the intervention, both of which have been shown to have an impact on implementation [317]. Furthermore, the majority of the studies evaluating IMR and WRAP have been conducted within the US. This questions the generalisbility of the results to the UK setting, where the level of standard care is different to that received in the USA.

In addition to recovery-orientated interventions which focus on self-management, the results of the thesis can also be compared to other recovery-orientated team or service level approaches, including Strengths-based models of care. The REFOCUS Intervention included the Strengths Assessment Worksheet, which was developed and as part of SBCM [208]. The decision to use the Strengths Assessment Worksheet was based on the findings of a

systematic review conducted as part of the REFOCUS programme [278]. Ten empirical studies involving the Strengths Assessment Worksheet as part of SBCM have demonstrated a range of positive effects, particularly in terms of pre and post intervention outcomes [211,329,330]. The positive findings of SBCM are consistent with the positive findings regarding the secondary outcomes measured as part of the present study, which suggested that the intervention was associated with increases in levels of met need.

However, a recent meta-analysis of strengths-based approaches to service delivery, which included but was not restricted to SBCM, failed to quantitatively find any advantage for strengths-based models over standard care [331]. The review noted that fidelity to a strengths-based approach was unclear in most studies. In particular, it was often hard to distinguish between the strengths-based model of care, and the alternative model being investigated, with the features of both models significantly overlapping [331]. This lack of distinction between the strengths interventions reviewed and standard care is in part consistent with the present thesis. Within the trial, there were no differences in fidelity (as measured by the RFS-SU) between the intervention and control groups, and between the baseline and endpoint assessments. This finding is also consistent with the fourth explanation for lack of effect given in Section 9.2.4, which suggested that staff were already using elements of the intervention within routine practice.

Psychosocial Interventions.

In addition to the comparison with recovery-orientated interventions, the development of the REFOCUS intervention can also be compared to other existing interventions for people with psychosis. In particular, comparisons can be made with individual and group-based psychosocial interventions.

A meta-analysis has recently been conducted comparing psychosocial interventions for people with psychosis [332]. The review and meta-analysis included 48 trials which were grouped into six interventions, namely befriending, CBT, Cognitive remediation, psychoeducation, social skills training and supportive counselling. Overall, there was evidence that CBT was the most efficacious intervention for people with psychosis, in terms of symptom reduction. CBT was originally developed in the 1960s and 70s as a treatment for depression and was later adapted to other conditions including psychosis [333]. CBT has also been shown to be effective for

other mental health problems including psychosis with co-morbid substance misuse [334], social anxiety [335] and for specific problems such as aggression and violence [336]. Although there is a current debate regarding the magnitude of the effects of CBT for psychosis, there is consistent systematic review evidence that CBT is associated with positive effects [337].

Compared to the REFOCUS intervention, and the current evidence for other recovery-orientated interventions such as WRAP and IMR, the evidence base for psychosocial interventions, and CBT in particular, is more advanced. This includes a greater number of RCTs, which for the psychosocial interventions reviewed by Turner and colleagues, ranged from 8 to 22 [332]. This compares to the recovery literature, which was marked by a lack of empirically-based evidence particularly RCT evidence. This lack of RCT evidence provided the rationale for a cluster RCT within the present thesis. However, unlike a lot of earlier CBT and psychosocial intervention trials, the REFOCUS study was pragmatic in nature, and was not a tightly controlled efficacy study, or a pilot study. There is evidence to suggest that as trials move from pilot to efficacy and then pragmatic studies, the effect size associated with the intervention reduces [338]. This is due to the presence of both real-world complexity within the results, and more sophisticated trial methodology which reduces the level of bias and subsequently the effect size [337].

9.3 Strengths and limitations

Before discussing the scientific, clinical and research implications, the strengths and limitations of the trial will now be discussed alongside the overall strengths and limitations of the thesis. Specific strengths and limitations of earlier chapters, including the systematic review (Chapter 3) and the qualitative study (Chapter 5) have been previously discussed in their relevant chapters and are briefly summarised here.

9.3.1 Strengths

The thesis had seven strengths covering both conceptual and methodological strengths.

Firstly, this thesis is the first empirical investigation of the meaning of recovery for people from black backgrounds who use CMHTs within the UK. Mary O'Hagan has described the recovery literature as very *"monocultural"* ([28] [p2]), with a lack of attention to race, culture and ethnicity. Furthermore, much of the earlier recovery literature paid little attention to the differences between people and groups of people, including their social context [339]. Rodgers notes that within psychiatry in general, there is a lack of evaluative work conducted

within different cultures and contexts including evaluating the feasibility, acceptability and effectiveness of different interventions for individuals from minority backgrounds [171]. With specific reference to recovery interventions, Pilgrim states that the influence of social structure including race, gender and class has not been adequately addressed [112]. This knowledge gap was addressed within the present thesis through the development of a Framework of Recovery Support and culturally-sensitive pro-recovery intervention.

The second strength of the thesis was the theory-driven development of the REFOCUS Intervention. The thesis used the MRC guidance as a scientific framework [31]. A common criticism of the research into recovery has been the lack of empirical evidence base. This thesis directly addresses this limitation and has provided new empirical knowledge about the meaning of recovery and effectiveness of a recovery intervention for black individuals.

The third strength of the thesis relates to the culturally competent and sensitive manner in which the main qualitative component of this thesis was designed and conducted. As previously discussed in detail in Section 5.4, this included giving individuals the choice to have interviewers from black backgrounds, and being mindful of cultural practices. Previous research has highlighted the importance of cultural and religious sensitivity in conducting research with individuals from BME backgrounds, including ensuring individuals have a positive experience of the research [340,341].

The fourth strength relates to the overall design of the cluster RCT, which included a nested process evaluation. Lewin and Colleagues describe how 30 out of 100 trials included in their review used qualitative methods alongside quantitative data collection as part of an intervention trial [51]. However, their review highlighted how many papers failed to provide adequate details of the qualitative methods used. This included inadequate information about sampling and data collection, and little or no integration of the qualitative and quantitative data [51]. Within the present thesis, detailed methods of the process evaluation were described in Chapter 7. Particular attention was paid to integrating the results of the qualitative and quantitative data sources both at the analysis and interpretation stages of the project.

Fifthly, the overall mixed methods design of the thesis can be seen as a methodological strength. Within healthcare research, mixed method research has been argued to be the "*Gold standard*" [[342] p613], as it captures the complexity of real-world situations. This thesis

used an experimental embedded design, in which qualitative data collection preceded and was then embedded within a larger quantitative component [48].

Creswell and colleagues outline five criteria they propose to rate the quality of mixed methods research [343]. The five criteria and how they were addressed in the thesis are presented below:

- Rationale for mixing was provided in Section 1.4. A subtle realism perspective was the underlying study epistemology, which was consistent with a mixed methods approach to answer the research question.
- Details about the forms of data collected was provided for the thesis as a whole in Section 1.4.8. Furthermore, specific details about the forms of data collection were addressed in the individual chapters which included a methods section where appropriate.
- Analytical procedure as above was described in the individual chapters.
- Characteristics of the design such as priority and sequencing of implementation were diagrammatically represented in Figure 1.3.
- Integration of findings was explicitly addressed from the outset, with a novel SEM analysis conducted in Section 8.4.

The pragmatic nature of the trial is the sixth strength of the thesis as it potentially means the results are more applicable to routine practice [321]. Despite the pragmatic nature, attempts were made to address each of the areas included in the Cochrane risk of bias tool [306]. In order to minimise selection bias, the study aimed to recruit individuals into the trial prior to randomisation. Baseline characteristics of participants (as shown in Table 8.2) suggests that selection bias was minimised with only one outcome measure (HoNOS) significantly differing between the control and intervention group. Baseline differences between individuals in the different arms of the trial can have an impact on the outcomes, especially if not adequately controlled for in the analysis [344,345]. Additionally, randomisation at the cluster level (i.e. team level) was conducted by the Clinical Trial Unit, who were independent of the research team.

The final strength of the trial relates to the *a priori* nature of the sub-group analysis. Previous researchers for example, [346,347,348,349] have identified a number of issues with the use of *post hoc* sub-group analyses in larger trials. In particular, the lack of *a priori* specification of sub-groups, post-randomisation assessment of sub-group characteristics and inadequate (or

no) power calculations are common problems within the literature. Decisions regarding the use of a sub-group in the present thesis were made *a priori*, and were included in the published trial protocol. In line with best practice [349], power calculations were conducted (reported in Section 7.6.1) and assessment of eligibility into the sub-group was determined prior to randomisation. This ensured that randomisation was maintained so that the sub-group analysis of black individuals meets criteria for a stand-alone RCT.

Furthermore, Rothwell suggests that subgroup analyses should only be considered where there is evidence of potential differences between groups, particularly where one group is likely to have a poorer outcome than the other [347]. As described in Chapter 2, the ethnic inequalities in mental health care provided a clear rationale for the sub-group analysis as black individuals were shown to have a poorer experience of care.

9.3.2 Limitations

There were eight limitations of the thesis which cover both conceptual and methodological issues. Additional limitations of the thesis are also included in a summary table (Table 9.1) following discussion of the eight main limitations.

Firstly, although the thesis fully addressed the development and evaluation stages of the MRC framework [31], it was not possible within the timeframe of the overall REFOCUS project to pilot the intervention prior to the cluster RCT. The addition of a pilot phase may have helped improve the implementation of the intervention, and may have provided more accurate estimates of treatment effect on which to base the power calculations for the definitive RCT [350].

The second limitation relates to cultural relativity. As discussed in Section 5.4, the impact of being a white individual and researching sensitive areas such as race, culture and ethnicity needs to be considered. In line with a subtle realism perspective, reflexive memos were kept to record my views on how my own cultural and ethnic background may have had an impact on the data collected. Furthermore, as outlined in Section 5.4, a number of approaches were used throughout the study to minimise this impact.

Linked to the above limitation, the advantages and disadvantages of belonging to a similar ethnic group and sharing the experiences of participants have been highlighted by previous research. Although in some cases sharing the same ethnicity may help individuals to feel more

comfortable with the researcher, in other cases, this was linked to concerns about confidently within the community. A shared ethnicity could also be a barrier to participants fully clarifying the meaning of some phrases or opinions, as it was assumed that the interviewer understood the concepts being discussed [351]. Furthermore, matching just one of the elements of identity such as ethnicity does not attend to the other areas of identity which are important to the person.

Additionally, the thesis and in particular the RCT focused on black individuals, which relates to a category broadly based on race. In taking this approach, the range of ethnicities included within this category may be ignored. Although this grouping is consistent with the approach often taken within services, where individuals are frequently described in terms of broad racial categories, one major limitation is that this grouping can serve to reinforce a race-based view of ethnicity and identity. Furthermore, such categorisation may serve to perpetuate racial groupings within research and practice. Although this grouping served a pragmatic purpose such that it allowed for stratification of individuals within the RCT, it must be stressed, that throughout the thesis a nuanced understanding of ethnicity was applied (as described in Section 1.2.1). Throughout the thesis, and in particular within the qualitative sections, self-definition was used to determine ethnicity. Furthermore, the importance of other areas of an individual's identity such as their culture, their social roles and personal characteristics was stressed throughout.

The third limitation relates to the lack of interpretation services. This meant that individuals who were unable to speak and understand English were excluded from participation. This may impact on the generalisability of the findings. When aiming to understand the meaning and experience of recovery, a broad range of individuals, including those with different ethnic identities is recommended [352]. Excluding individuals who were unable to speak English reduces this diversity. Future research could aim to address this limitation through the use of interpretation services.

The remaining limitations of the thesis, all relate to methodological issues, particularly regarding the cluster RCT. Although overall, methodological rigour was a strength of the thesis, there were a number of methodological challenges encountered in the cluster RCT. These design challenges would need to be addressed in a further efficacy trial, although many of the challenges relate to the more pragmatic nature of the trial and the routine implementation of the intervention [286].

Blinding was the fourth limitation of the thesis and represented one of the major methodological concerns within the cluster RCT. Within a trial, different individuals can be blinded. This includes the participants receiving the intervention (service users in REFOCUS), the personnel delivering the intervention (staff members), the research team conducting the outcome assessments, and the statistician conducting the analysis [353,354]. As with most psychosocial and team-level interventions using standard care as a control, it was not possible to blind service users and staff to allocation status. Specifically, within the present trial, both staff members and service users were invited to attend information sessions providing them with details about the intervention. These sessions were conducted by the researchers on the REFOCUS project. Researchers also provided staff with promotional materials and problem-solved where implementation issues arose. The lack of blinding and the interaction with the research staff may increase the chances of participants answering in a socially desirable way.

Although it was planned that outcome assessors would be blinded to intervention allocation (discussed in section 7.10.10), in practice this was not possible. As previously stated, the REFOCUS researchers, worked alongside trial teams and staff members to support effective implementation. Additionally, for pragmatic reasons researchers needed to be aware of the team location for each person when arranging the follow-up. As this was a cluster RCT, knowing the team location meant researchers were aware of the allocation status of participants. Within meta-analyses, blinding of the participants and outcome assessors has been shown to have a significant effect on the results of the analysis, for instance effect sizes in studies with inadequate blinding were inflated by 17% compared to studies with adequate blinding [355]. Future trials should ensure that only selected members of the research team are aware of the allocation status, with independent researchers used for data collection.

The fifth limitation relates to a lack of power for both the main analysis of treatment effect and for some of the secondary outcomes. Although the number of participants for the main outcome was consistent with the power calculations (presented in section 7.6.1), this was based on an anticipated effect size of 0.67. Given that individual and group-based interventions such as CBT and family intervention have demonstrable effect sizes of approximately 0.3 [337], this suggests that the anticipated effect size was too large for the intervention tested within the thesis. Using a more conservative effect size consistent with other psychosocial interventions would increase the number of participants needed.

Consequently, the RCT was underpowered to detect a more conservative and/or realistic effect size.

Furthermore, the number of individuals with data for some of the secondary outcomes (e.g. BPRS) were lower than needed for the power calculations). As discussed in Section 9.2.1, overall, the drop-out rate for black participants was equivalent to the overall trial, suggesting that the intervention was equally acceptable. However, for some measures (e.g. BPRS) the number of participants with data in the analysis was less than required in the power calculations. Systematic drop-out of participants may lead to bias in the results. For example, if individuals who are less well drop out during the intervention, the effect of the intervention on symptoms may be inflated [353,356]. The level of drop out across the different outcome measures had implications for the type of analysis conducted. In particular, given the clustering at the different levels, and also the small numbers within each cluster, it was not possible to conduct a CACE analysis [286].

The sixth limitation, which is linked to the above, relates to the number of outcomes assessed. Within a regression analysis, increasing the number of covariates relative to the number of observations can inflate the resulting beta coefficients and the significance of the different variables. In such cases where over-fitting occurs, the model reflects random error and minor fluctuations in the data instead of true underlying effects or relationships. Furthermore, in an over-fitted model, the explanatory power of each variable is low [357]. The results of the post-hoc sensitivity analyses suggested that the results of the multilevel, mixed-effects modelling was over-fitted and hence produced spurious findings. When the number of observations within the analysis were increased through multiple imputation, the significant effects observed were no longer present. This would suggest that either the number of outcomes assessed needed to be reduced, or a composite measure created. Furthermore, the choice of QPR as a primary outcome was also limited by the lack of available psychometric data for black individuals. Although some psychometric properties have been published for the QPR (as discussed in Section 7.9.1), this has not specifically focused on black individuals within the UK. Additionally, sensitivity to change has not currently been established for the measure. Future work using the trial data could potentially address this limitation and provide some psychometric data for black individuals within the UK, including sensitivity to change.

The seventh limitation of the trial was in the use of clinical records (EPJ) to determine ethnicity and hence inclusion within the study. This meant relying on routinely available data

rather than self-ascribed ethnicity. As discussed in Section 1.2.1, as ethnicity relates to a fluid concept involving a sense of belonging, self-ascribed ethnicity is preferred over routinely collected data, which may base judgements on certain features of ethnicity such as race [9]. The decision to use clinical records was pragmatic as it allowed the stratification of the caseloads prior to random selection. Furthermore, within the trial it was not possible due to the low numbers to look at different ethnic groups, e.g. black African, Nigerian, Jamaican etc. However, future research could aim to explore this in more depth given the heterogeneity of the category 'black' and the cultural variation between different ethnicities included within the trial.

The final limitation of the thesis was the decision to only focus on the perspectives of service users and not staff within the intervention teams. Including the staff perspective within the process evaluation may have given a better indication of the implementation of the intervention within routine practice. Although the staff perspective was included in the main REFOCUS trial, it was beyond the scope of the present thesis.

The limitations of the thesis discussed above are summarised in Table 9.1 .

Table 9.1: Limitations of the thesis

Limitation	Description
Assessing only two stages of the MRC framework	Although the MRC framework for designing and evaluating complex interventions was used as the scientific framework for the thesis, it was not possible to adequately address Stage 2 feasibility and piloting within the project.
Cultural relativity	One consideration throughout the thesis related to cultural relativity and potential issues raised by being a white researcher addressing sensitive areas such as ethnicity.
Use of black as a category within the thesis	The focus of the thesis was on black individuals, however this category uses a racial classification based on skin colour, and does not attend to the diversity in ethnicities and cultures within this category.
Lack of interpretation services	It was not possible to provide interpretation services throughout the thesis, therefore the views of individuals who were unable to speak and understand English were not included.
Lack of blinding of personnel, service users and researchers	One methodological limitation encountered within the RCT was the lack of blinding. In particular, staff delivering the intervention, individuals receiving the intervention and researchers assessing outcomes were not blind

Limitation	Description
	to treatment allocation which may bias the results.
Lack of power to detect changes in secondary outcomes	Although approximately 75% of individuals were followed up for the primary outcome, the number of individuals for some secondary outcomes was lower than that indicated within the power calculations.
Lack of power for the primary outcome	The power calculations were based on a previous non-randomised study which produced a large effect size of 0.67. Consequently, the study was underpowered to detect a more conservative or reasonable effect size of 0.3, which is consistent with other psychosocial interventions.
Use of QPR as the primary outcome	The QPR was used as the primary outcome measure. Although the measure was developed for a UK population, sensitivity to change at the time had not been established. Furthermore, the measure had not been validated for black individuals.
Number of outcomes assessed	Due to the large number of outcomes included in the trial and in the subsequent analysis, the regression models were over fitted.
Use of clinical records (EPJ) to determine inclusion status	For the RCT, ethnicity and hence inclusion status was based on the clinical information system (EPJ) and not on self-ascribed ethnicity.
Path direction in the SEM analysis	The SEM analysis conducted within the thesis was an exploratory analysis which indicates an association between variables and not causation. Although the path tested in the analysis was based on the Framework of Recovery Support, alternative pathways could also be a plausible fit to the data.
Focusing on only the service user perspective	The focus throughout the RCT was on service user outcomes and perspectives, however including staff perspectives may have helped understand implementation issues within the trial.
Lack of measurement of staff fidelity to the intervention	Finally, although measured as part of the overall REFOCUS RCT, measures of staff fidelity to the intervention were not included in the present thesis.

9.4 Implications of the thesis

9.4.1 Scientific implications

The thesis has scientific implications for the REFOCUS Intervention, the REFOCUS Model and the process evaluation methods.

Implication 1: Modifications to the REFOCUS Intervention

In addition to understanding the experience of the participants included in the trial, the process evaluation was used to identify potential modifications to the content of the intervention and the way in which it was delivered. Participants in the process evaluation indicated that the following three modifications would improve the Working Practices to make them more effective in supporting personal recovery.

Firstly, there was a need to better explain why the new conversations, and in particular the new topics covered in the VTP Interview Guide, were being asked. Individuals reported that without any prior warning these new areas could be perceived as either intrusive or indicative of a problem. This suggests that the training delivered as part of the intervention needs to address the way in which the Working Practices are introduced.

Secondly, service users stressed the importance of ensuring that any information discussed during the Working Practices needed in some way to be used and not just recorded. For example, service users found it helpful when values, treatment preferences, strengths and goals were used to inform care-planning and when action was taken as a result. This suggests that the Working Practices need to be modified to explicitly highlight how information discussed should be taken forward into care planning. This could be covered either through training, or providing further resources within the intervention to enable staff to achieve this aim.

Finally, individuals stressed that the Working Practices needed to be conducted within the context of a recovery-supporting relationship. Just asking the questions included in the intervention was not sufficient to change the relationship between staff and service users and to improve personal recovery. Working Practices were perceived as useful when service users felt they reflected a genuine interest from staff, rather than being another *"tick-box exercise"*. An increased focus could be placed on using coaching skills to deliver the Working Practices.

In addition to suggested modification to the content and delivery of the Working Practices, two further modifications were suggested. These were i) raising awareness and ii) co-ownership of the intervention materials.

Within the process evaluation, individuals noted that they often had little awareness of the REFOCUS intervention or the REFOCUS trial. Consequently individuals were unaware of what

they could and should expect from their interactions with staff during the intervention period. Raising awareness of the intervention may help individuals to have expectations of recovery-promoting practice from staff. Although one implementation strategy of the REFOCUS Intervention was the provision of service user information sessions, these were poorly attended. One strategy to raise awareness may be through the development of service user materials such as a recovery handbook.

Linked to the above, the second suggested modification to the intervention was for the intervention materials to be co-owned by service users. Individuals suggested that service users should be given a copy of the manual and other materials such as the Working Practice tools. This would raise awareness of the intervention and help individuals to feel in control of their recovery. Encouraging individuals to have personal responsibility for their recovery and feeling in control were both important themes identified within the Conceptual Framework. This approach is currently being trialled in the Principles Unite Local Services Assisting Recovery (PULSAR) project which has received funding from the Victoria Government to test the REFOCUS intervention within mental health services in Victoria, Australia [358].

Implication 2: Modifications to the REFOCUS Model

In addition to the two suggested intervention modifications, the results of the trial highlighted how satisfaction with care has both a direct and indirect effect on recovery, suggesting that the REFOCUS Model should be adapted. The REFOCUS Model, therefore could be adapted to explicitly include satisfaction with care as a proximal outcome alongside increased hopefulness and empowerment. The quantitative trial results also suggest the intervention reduces service user-rated levels of need. The trial results, in contrast, did not support the predicted impact on quality of life as a proximal outcome.

The modified REFOCUS Model is shown in Figure 9.1.

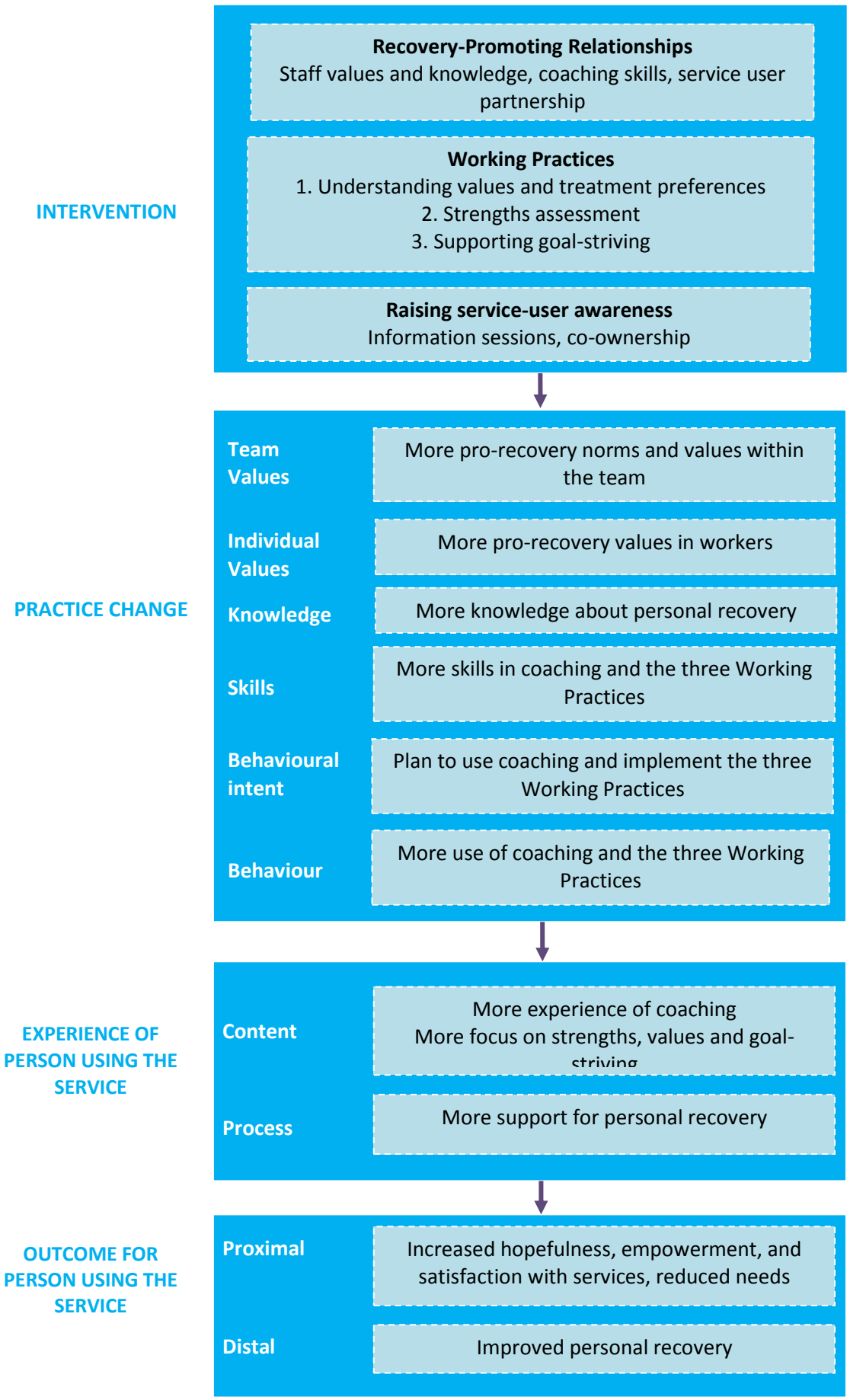


Figure 9.1: Modified REFOCUS Model

Implication 3: Evaluation method

The thesis used the MRC framework and followed best practice regarding trial methodology and the inclusion of a nested process evaluation [48,51,359]. However, the intervention delivered was integrated within routine care and also targeted subtle changes in the relationship between staff and service users. Many service users were unable to describe the intervention changes. Therefore consideration could be given to how best to evaluate the intervention from the perspective of service users.

Alternative approaches to obtaining the service user perspective of a complex intervention such as REFOCUS may need to be considered. This could include ethnographic research in which the researcher is embedded within the social world and real-world setting of the research participants. Ethnographic methods such as participant observation or the recording of interactions may be more useful in detecting subtle changes as a result of the intervention. Action research which actively involves the individuals receiving the intervention in the research process may be another option to consider. However, these ethnographic methods are not without limitations. For example, by being embedded within the participant's world, the nature of interactions may be changed or subject to social desirability. Furthermore, such methods tend to be time consuming and expensive [360,361]. An alternative may be to make the intervention more visible within clinical interactions, either through the use of service user held intervention materials or by raising awareness using branded materials.

9.4.2 Clinical implications

The work conducted in this thesis has contributed to knowledge by providing a Framework of Recovery Support for black people which highlighted the barriers and facilitators of recovery and how best to support recovery within and outside mental health services. The thesis has also contributed to knowledge by developing and evaluating a pro-recovery intervention, including a component specifically linked to the Framework of Recovery Support. These knowledge contributions have at least six clinical and practice implications which are outlined in Box 9-1 , and then discussed in detail.

Implication 1: The VTP Interview Guide offers one way for clinicians to explore the person's identity and develop a personal narrative.

Implication 2: The qualitative sections of the thesis suggest that clinical encounters need to consider the experience of belonging to a stigmatised group and the impact this can have on illness and recovery.

Implication 3: The VTP Interview Guide and Working Practice may help address *'professional paralysis'* in terms of discussing race, culture and ethnicity.

Implication 4: The qualitative sections of the thesis add knowledge to the debate regarding BME specialist services.

Implication 5: The qualitative sections of the thesis add knowledge to the debate regarding the ethnic matching of staff and service users.

Implication 6: The VTP Interview Guide can be used to help understand the treatment preferences of the person and their previous experience of services, including any experiences of a lack of access to talking therapies.

Box 9-1: Clinical Implications of the Thesis

Identity and recovery

Within the Framework of Recovery Support, (re)gaining a positive sense of self was central to the experience of recovery. The importance of staff focusing on all areas of identity was validated by the trial data. Individuals described previous experiences within services where assumptions about the person were made on the basis of ethnicity and broad racial categorisations. These assumptions included decisions about the person's treatment, such as access to BME services, often without consultation with the individual concerned.

The Breaking the Circles of Fear report proposed that one way to overcome the negative experience of individuals within services was for a whole person approach to be used, with a strong emphasis on identity [81]. The Framework of Recovery Support highlighted the importance of different areas of identity to the person. The VTP Interview Guide and Working Practice encouraged staff to take a wide definition of identity and to view identity as fluid. This was encouraged through the suggestion that discussions about identity should not just be a one-off, but should regularly explore what is important to the person.

Consistent with this idea, a study which explored identity within the recovery process of people experiencing a first-episode of psychosis, highlighted the fluidity of identity [362]. This suggests that clinical interactions should focus on a holistic person-centred approach to finding out about the values and the identity of the person on a regular basis. The Values and Treatment Preferences Working Practice offers clinicians one way of achieving this aim.

Further to this, as discussed in Section 5.5.3, the Social Identity Approach may be important to consider, particularly when understanding the impact of mental illness and societal

discrimination on a person's sense of self. Social identity builds on Tajfel's social identity theory and Turner's self-categorisation theory to help explain intergroup processes, and the development of the sense of self [247]. Social Identity concerns social relationships and how social factors influence the individual's self concept. The development of the self-concept is seen as a dynamic and changing process, influenced by the experiences and social world of the person [247]. A review of social identity in the experience of depression found that social connectedness was key to recovery, with the ability to maintain a positive sense of self being a protective factor against depressive episodes [246].

Individuals within the study made reference to belonging to multiple disadvantaged backgrounds, with part of their social identity comprising group membership to undervalued groups within society. Identity negotiation may be one way that individuals can overcome the negative impact of belonging to multiple stigmatised groups. Identity negotiation reflects the process of managing a change in identity, and particularly the loss of a valued identity. Identity negotiation is marked with a transition between identities, where individuals seek to self-verify their identifies and seek positive evaluations from other. Identity negotiation may be preceded by an identity conflict or crisis. During an identity crisis, there may be conflicts between the individuals different personal and social identities [249]. For example, in the present study, conflict may arise between wanting to return to the same person as before, and needing to adapt and develop a new identity. Consistent with this, empirical investigation of identity change following acquired brain injury highlighted how personal and social changes to the person's identity were linked to quality of life and wellbeing [363].

In line with the Framework of Recovery Support, the clinical implications of a social identity approach would include supporting individuals to explore different elements of their identity, and helping people to foster and maintain social relationships that are important to their sense of self. As suggested above, this may involve a person-centred and more holistic approach to care planning, potentially involving the VTP Interview Guide and Working Practice. In particular, the VTP Interview Guide could be used in clinical encounters, particularly with individuals experiencing a first episode of illness, to understand the impact of illness on identity. Use of the tool may also help the individual remain connected with identities and groups important to their sense of self. This may include taking a more collectivist approach and viewing the person in their social context, including the role of the family and community.

Multiple disadvantaged groups

A second clinical implication of this thesis related to how individuals within the qualitative study discussed belonging to multiple disadvantaged groups and the need for this to be considered within clinical encounters. As discussed in Chapter 3 and Chapter 5, the importance of identity and a positive sense of self were not specific to black individuals. Instead, the Conceptual Framework of Personal Recovery included identity as one of the five recovery processes. Many studies included in the review highlighted the importance of identity and feeling positive about the self for individuals from a range of backgrounds, including minority e.g. [154] and majority populations e.g. [8]. For all individuals, overcoming the negative effects of mental illness, including the associated stigma, was seen as important to recovery.

Previous research has shown that individuals from black communities face multiple sources of disadvantage and stigmatisation [3,97,154,163]. These findings are consistent with a previous study - ENRICH, which aimed to improve outcomes and reduce health inequalities for individuals from BME backgrounds [3]. The stigma associated with mental health was in addition to the stigma associated with being black in a predominantly white society. Within this thesis, individuals described experiences of racism and discrimination, alongside tougher economic conditions including social adversity and unemployment. These social aspects had a negative impact on both the person's mental health and their sense of identity. These two sources of threat to identity, i.e. societal and illness, were included in the Framework of Recovery Support.

Consistent with the above, research has demonstrated how actual and perceived disadvantage [86,87], and the perception of racism [364] are important in the development of mental health problems, and contribute to the inequalities experienced by black individuals. A recent report by the National Centre for Social Research indicated that the percentage of individuals who admitted to being racially prejudiced had increased since 2000, with 29% of people surveyed indicating they had some level of racial prejudice [365].

The impact of being part of a negatively stigmatised community, in addition to the negative effect of having a mental illness has clinical implications. To support the recovery of black individuals, a wider societal perspective is needed. This wider perspective may mean that mental health services and staff need to explore and consider the influence of different levels of disadvantage on the person's sense of self and how these multiple areas of disadvantage

can be overcome to promote recovery. Furthermore, it could be argued that the findings of the qualitative sections of this thesis suggest that the role of mental health services should be expanded to address disadvantage. This may include, for example, taking mental health into the community, addressing issues of societal stigma through education and linking with community-based voluntary sector organisations.

Professional paralysis

Research has highlighted that there is a lack of opportunity for individuals to discuss the impact of disadvantage, including racism and discrimination with mental health staff. This was echoed in the present thesis, where individuals talked about the impact of racism on their mental health, yet often mentioned that they were unable to have these discussion with staff. This has been termed *'professional paralysis'* [81]. It was further suggested that mental health staff often avoided discussions concerning race and culture as these were seen as taboo subjects.

The Working Practice developed as part of this thesis, and the Intervention overall may offer clinicians one way of overcoming professional paralysis. Specifically, the VTP Interview Guide encourages wider discussions about the person's identity, places a strong emphasis on supporting and identifying different areas of a person's identity and emphasises that multiple aspects of the person are important to their sense of self, not just their mental illness.

BME specialist services

The fourth clinical implication of the thesis relates to the addition of knowledge to the debate regarding the provision of specific BME services. Previous research has suggested that the needs of BME individuals would be best addressed by the provision of specific services [81]. Many examples of good practice regarding overcoming ethnic inequalities within the literature relate to BME specialist services in both statutory and particularly within the voluntary sector [11,81,94].

However in contrast to this view, findings from the ENRICH study concerning individuals experiencing a first episode of mental illness, indicated that there was no expressed desire for BME specific services. Instead, generic mental health services were seen as appropriate to the needs of individuals as long as people were able to discuss issues concerning race, culture and ethnicity with staff. This also included being able to have discussions around spirituality and religion [3]. This finding is consistent with the present thesis. Specifically with reference to the

provision of the right services which individuals felt would best support their recovery, individuals were mixed in their view on BME services. Many individuals noted the problems with basing services on a crude racially-based classification, and ignoring the different ethnicities of individuals defined as BME. Furthermore, as stressed within the qualitative study and the Framework of Recovery Support, it was important for individuals to be able to express their preferences for different types of services. The VTP Interview Guide and Working Practice may offer staff one way of discussing a person's preference regarding BME services. Such discussions could be had early in the person's care and frequently revisited to ensure services fit with the values of the person, where possible.

Ethnic matching

The fifth implication for clinical practice relates to the ethnic matching of staff and service users. As with the above research on BME specific services, the literature on ethnic matching is mixed. Singh and colleagues found that there was no overall desire for ethnic matching between staff and service users, with service users wanting to have caring and supportive staff regardless of their ethnicity [3]. In contrast, a consultation with black and minority ethnic mental health services users noted that having contact with and care from people from the same background and who shared similar experiences was perceived as helpful to recovery [97]. Furthermore a review of research aiming to enhance pathways to care for black and minority populations indicated that ethnic matching may be beneficial [366]. However, the studies included in the review were not conducted within the UK, raising the question of generalisability given the social, political and historical context of different ethnic groups varies in different countries and settings.

The mixed nature of these previous findings were also apparent in the present thesis, in which individuals varied on their opinion regarding ethnic matching. A further implication of this finding with reference to ethnic matching, is that it may not be ethnicity *per se* that is important, but instead the characteristics of the individual such as whether the service user feels understood, respected and cared for which are important to recovery. Linked to this is the idea of improving the cultural capability of the workforce through either cultural competency training or cultural consultation [367]. Consistent with this finding, a recent systematic review indicated that the therapist characteristics most associated with positive interactions and outcomes were therapist knowledge and multicultural competence [368].

Previous literature has shown that where research and services focus on ethnic matching, the danger is that ethnicity is used in a reductionist manner. This assumes that black service users will want a black staff member, without a more nuanced consideration of the person's ethnicity and ethnic identity. The findings from the present qualitative study indicate that what is important is finding out about the person's preferences, and re-visiting this throughout their treatment because previous experiences within the mental health services impact on what the individual wants from further staff and interventions. The VTP Working Practice and in particular the VTP Interview Guide explicitly included items relating to ethnicity and gender alongside the person's treatment preferences relating to this area.

Access to Talking Therapies

The final clinical implication relates to exploring the treatment preferences of individuals who used services. Throughout the thesis, individuals noted the lack of available treatment options offered, particularly with reference to talking therapies. This was consistent with the literature reviewed in Chapter 2, which highlighted access to services as a major concern for black individuals. The VTP Interview Guide and Working Practice allow staff to explore how the person's values have an impact on their treatment preferences. This includes exploring previous experiences of mental health services.

The use of the REFOCUS intervention to identify the treatment preferences of the individual is timely given the recent media attention on the provision of mental health services, and in particular talking therapies. Both the chief medical offer's report [369] and policy documents issued by mental health charities including MIND [370] have called for greater access to therapies such as CBT and those provided by IAPT for all mental health services. In particular, the MIND report highlighted that for all service users, over 40% of individuals had to request talking therapies rather than being offered them. Furthermore, the report noted that ethnic inequalities in the provision of talking therapies continued to persist, despite national guidance aiming to address this inequality [333]. In particular, individuals interviewed for the MIND report felt that services and therapies did not adequately address their cultural needs [370].

Despite access to psychosocial interventions being part of national guidance, implementation remains a challenge. For example, an audit of a mental health trust in Northern England which involved 187 randomly selected service users, indicated that only 6.9% had been offered, and less than 5% received the recommended individual CBT, whilst less than 2% were offered and

received family interventions [371]. This has led to national charities and lobbying groups to form the 'We need to talk coalition'. The coalition has called for the NHS to offer the full range of evidence-based psychological therapies to individuals within 28 days of requesting them [372]. Although the REFOCUS Intervention and the understanding Values and Treatment Preferences Working Practice cannot directly improve the provision of services for individuals, the tools offer one approach to assessing what treatments are preferred or requested by individuals, with the aim of providing person-centred care.

9.4.3 Research Implications

The results of the thesis have three implications for future research. Research could build upon the work conducted in this thesis to provide more knowledge regarding how best to support the recovery of black individuals using community mental health services.

One further area for research relates to the use and evaluation of the VTP Interview Guide within early intervention services. Within the current cluster RCT, early intervention teams were not included. However the qualitative process evaluation indicated that participants felt the VTP Interview Guide should be used in early interactions with staff to help staff get to know the individual. Further to this, the literature review conducted in Chapter 2 highlighted how ethnic inequalities in terms of pathways to mental health care and experience of care exist at the stage of the first episode [20,373]. Using the VTP Interview Guide at the first point of contact may help reduce the negative impact of these inequalities. A future study could assess the VTP Interview Guide within this service context.

Secondly, the use of the intervention and specifically the VTP Interview Guide could be considered for different populations which were beyond the scope of the present trial and thesis. This could include using the tools with inpatients or those within forensic settings. Given the research evidence that individuals from black backgrounds are more likely to experience adverse routes into care, including contact with forensic services and the CJS, the use of the VTP Interview Guide might help build a mutually trusting relationship between staff and service users.

Finally, the role of the family in recovery, not only in supporting the person with mental health problems, but also in undergoing their own recovery journeys has been highlighted by previous research [374]. The role of families and the community may be particularly important in the context of individuals from black backgrounds, especially those who identify

with a collectivist identity. As evidenced in both the systematic review conducted in Chapter 3, and the qualitative study reported in Chapter 5, the negative impact of mental illness extends to the whole family, where the additional stigma of belonging to a collectivist culture was discussed. Future research could explore the meaning of recovery for individuals who strongly identify with a collectivist identity, including the meaning of recovery for their family members.

9.5 Conclusion

This thesis has advanced the knowledge and understanding of the concept of recovery from the perspective of individuals from black backgrounds, including how to support recovery. Gaining or regaining a positive sense of identity was crucial to the recovery of black individuals who use community mental health services. In order to support recovery, services need to explore the areas that are important to the person and their sense of self. Individuals in the present study felt that services and staff made assumptions about their identity and their care, and that these assumptions were often based on characteristics such as race and ethnicity, or on the assumed culture of the person. Even where individual staff members were well-meaning, such assumptions could have a negative impact on a person's experience of care and their recovery.

Throughout the thesis and within the wider literature, individuals made reference to belonging to multiple stigmatised groups. This included having a mental health problem and being a black individual within society. These multiple levels of stigma had a negative effect on identity. It was through the exploration of identity and by focusing on the person as a unique individual with strengths, values and goals, that service users could regain a more positive sense of self. The intervention component developed as part of this thesis, namely Working Practice 1: Understanding Values and Treatment Preferences, aimed to enable the exploration of a person's identity. Although the intervention did not have a significant effect on either satisfaction or personal recovery, the exploratory analysis indicated that identity exploration was linked to improved satisfaction with care and personal recovery. Furthermore, the intervention was shown to increase the levels of met need.

Future interventions should focus on the exploration of identity and what is valued by the person right from the first contact with services. The negative perception of an individual within society suggests the need for recovery to extend beyond the domain of mental health

services. Instead, a wider societal perspective is needed to effectively promote the recovery of all service users, including black individuals who use adult community mental health services.

"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style."

Maya Angelou (1928 - 2014)

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Appendix 1: REFOCUS - BME Virtual consultation panel Information sheet

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REFOCUS - BME Virtual consultation panel Information sheet

The REFOCUS project is a five year (2009-2014) NIHR funded project which aims to make recovery a reality in mental health services. As part the overall REFOCUS programme I will be conducting a PhD which focuses on supporting the recovery of black individuals who use community mental health services. The rationale behind the PhD arises from the research into various ethnic inequalities in mental health care e.g. increased rates of involuntary detention, more complex pathways to care and higher levels of involvement with forensic services for people from Black and Minority Ethnic (BME) backgrounds. It was also apparent from the recovery literature that although the recovery movement is increasing in momentum, much of the research has been primarily focused on majority populations, with a lack of research assessing issues of culture and ethnicity. The PhD will aim to address some of these issues, with the aim of informing the REFOCUS manual to help increase the cultural sensitivity of the intervention. The project follows along the same lines as other projects that have been conducted as part of the Delivering Race Equality (DRE) programme. We intend to follow examples of good practice, such as that of Fanon and Southside partnership in their community engagement project.

To achieve our aim we are recruiting members to form a BME Virtual Consultation Panel. It is hoped that this panel will provide a consultation resource throughout the study to ensure that we are considering ethnicity, race and culture at all stages. We also hope the panel will assist with the recruitment of people from BME backgrounds into different sections of the study, including BME specific focus groups and individual interviews.

I would like to invite you to join the BME Virtual Consultation Panel, and would very much value your input as a person with lived experience of mental health

services. The other people being invited to join are people with lived experience of mental health services, staff within the NHS and voluntary sector organisations with experience of working with individuals from BME communities and researchers involved with the REFOCUS study.

As with any consultation panel, participation is entirely voluntary. If you do decide to become a member, you will be asked by email to give comments on outputs and design issues arising in the REFOCUS Study. Time commitment will be kept to a minimum and (as this is a virtual panel) members will need to have access to email.

Terms of reference

The overall aim of the panel are to support the REFOCUS Study to consider issues of race, culture and ethnicity, especially in relation to participation in the study by people from Black and Minority Ethnic communities.

Specific contributions will include:

- providing a virtual consultation resource to comment on outputs from the study within a designated consultation period
- assisting in designing culturally-sensitive recruitment approaches
- helping identify gaps in the research which need to be addressed in future research
- highlighting information regarding the impact of race, culture and ethnicity to the other REFOCUS advisory panels.

Appendix 2: Publications corresponding with Chapter 3

Two papers corresponding to the content presented in Chapter 3 were published and are presented here.

Paper 1: Conceptual Framework paper

Leamy, M.,[*] **Bird, V.J.,**[*] Le Boutillier, C., Williams, J., Slade, M. (2011) Conceptual Framework for personal recovery in mental health: systematic review and narrative synthesis. British Journal of Psychiatry, 199(6), 445-52

*Denotes joint first authors

Abstract

Background

No systematic review and narrative synthesis on personal recovery in mental illness has been undertaken.

Aims

To synthesise published descriptions and models of personal recovery into an empirically-based Conceptual Framework.

Method

Systematic review and modified narrative synthesis.

Results

97 papers were included from 5,208 papers identified and 366 reviewed. The emergent Conceptual Framework consists of: i) thirteen Characteristics of the Recovery Journey; ii) five Recovery Processes comprising Connectedness, Hope and optimism about the future, Identity, Meaning in life and Empowerment (giving the acronym CHIME); and iii) Recovery Stage descriptions which mapped onto the Transtheoretical Model of Change[1]. Studies focused on recovery for Black and Minority Ethnic (BME) individuals showed a greater emphasis on Spirituality and Stigma and also identified two additional themes: Culturally specific facilitating factors and Collectivist notions of recovery.

Conclusions

The Conceptual Framework is a theoretically-defensible and robust synthesis of people's experiences of recovery in mental illness. This provides an empirical basis for future recovery-orientated research and practice.

Declaration of interest

None.

Introduction

Personal recovery has been defined as "*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles…a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness*"[2]. A recovery orientation is mental health policy in most Anglophone countries. For example, the mental health plan for England 2009-2019 has the "*expectation that services to treat and care for people with mental health problems will be…based on the best available evidence and focused on recovery, as defined in discussion with the service user*"[3]. The implications of a recovery orientation for Working Practice are unclear, and guidelines for developing recovery-orientated services are only recently becoming available[4;5]. Comprehensive reviews of the recovery literature have concluded that there is a need for conceptual clarity on recovery[6;7]. Current approaches to understanding personal recovery are primarily based on qualitative research[8] or consensus methods[9]. No systematic review and synthesis of personal recovery in mental illness has been undertaken.

The aims of this study were (i) to undertake the first systematic review of the available literature on personal recovery and (ii) to use a modified narrative synthesis to develop a new Conceptual Framework for recovery. A Conceptual Framework, defined as "*a network, or a plane, of interlinked concepts that together provide a comprehensive understanding of a phenomenon or phenomena*"[10], provides an empirical basis for future recovery-orientated research and practice.

Method

Eligibility criteria

The review sought to identify papers that explicitly described or developed a conceptualisation of personal recovery from mental illness. A conceptualisation of recovery was defined as either a visual or narrative model of recovery, or themes of recovery, which emerged from a synthesis of secondary data or an analysis of primary data. Inclusion criteria

for studies were: (i) contains a conceptualisation of personal recovery from which a succinct summary could be extracted; (ii) presented an original model or framework of recovery; (iii) was based on either secondary research synthesising the available literature or primary research involving quantitative or qualitative data based on at least three participants; (iv) was available in printed or downloadable form; (v) was available in English. Exclusion criteria were: (a) studies solely focusing upon clinical recovery[5] (*i.e.* using a predefined and invariant 'getting back to normal' definition of recovery through symptom remission and restoration of functioning); (b) studies involving modelling of predictors of clinical recovery; (c) studies defining remission criteria or recovery from substance misuse, addiction or eating disorders; and (d) dissertations and doctoral theses (due to article availability).

Search strategy and data sources

Three search strategies were used to identify relevant studies: electronic database searching, hand searching and web based searching.

1. Twelve bibliographic databases were initially searched using three different interfaces: AMED; British Nursing index; EMBASE; MEDLINE; PsycINFO; Social Science Policy (accessed via OVID SP); CINAHL; International Bibliography of Social Science (accessed via EBSCOhost and ASSIA); British Humanities Index; Sociological abstracts; and Social Services abstracts (accessed via CSA Illumina). All databases were searched from inception to September 2009 using the following terms identified from the title, abstract, key words or medical subject headings: ('mental health' OR 'mental illness$' OR 'mental disorder' OR mental disease' OR 'mental problem') AND 'recover$' AND ('theor$', OR 'framework', OR 'model', OR 'dimension', OR 'paradigm' OR 'concept$'). The search was adapted for the individual databases and interfaces as needed. For example, CSA Illumina only allows the combination of three 'units' each made up of three search terms at any one time e.g. ('mental health' OR 'mental illness*' OR 'mental disorder') AND 'recover*' AND ('theor$' OR 'framework' OR 'concept'). As a sensitivity check, ten papers were identified by the research team as highly influential, based on number of times cited and credibility of the authors (included papers 3, 9, 10, 19, 29, 34, 35, 40, 68 and 75 in Online Data Supplement 1). These papers were assessed for additional terms, subject headings and key words, with the aim of identifying relevant papers not retrieved using the original search strategy. This led to the use of the following additional search terms: ('psychol$ health' OR 'psychol$ illness$' OR 'psychol$ disorder' OR psychol$ problem' OR 'psychiatr$ health', OR psychiatr$ illness$' OR 'psychiatr$ disorder' OR 'psychiatr$ problem') AND 'recover$' AND

('theme$' OR 'stages' OR 'processes'). Duplicate articles were removed within the original database interfaces using Reference Manager Software Version 11.

2. The table of contents of journals which published key articles (Psychiatric Rehabilitation Journal, British Journal of Psychiatry and American Journal of Psychiatry) and recent literature reviews of recovery (included papers 4, 37 and 89 in Online Data Supplement 1) were hand-searched.
3. Web-based resources were identified by internet searches using Google and Google Scholar and through searching specific recovery-orientated websites (Scottish Recovery Network: www.scottishrecovery.net; Boston University Repository of Recovery Resources: www.*bu.edu/cpr/repository/index.html*; Recovery Devon: www.recoverydevon.co.uk; and Social Perspectives Network: www.spn.org.uk).

Data Extraction and Quality Assessment

One rater (VB) extracted data and assessed the eligibility criteria for all retrieved papers with a random sub-sample of 88 papers independently rated by a second rater (JW or CL). Disagreements between raters were resolved by a third rater (ML). Acceptable concordance was predefined as agreement on at least 90% of ratings. A concordance of 91% agreement was achieved. Data were extracted and tabulated for all papers rated as eligible for the review.

Included qualitative papers were initially quality assessed by three raters (VB, JW and CL) using the RATS qualitative research review guidelines[11]. The RATS scale comprises 25 questions about the relevance of the study question, appropriateness of qualitative method, transparency of procedures, and soundness of interpretive approach. In order to make judgements about quality of papers, we dichotomised each question to yes (1 point) or no (0 points), giving a scale ranging from 0 (poor quality) to 25 (high quality). A random sub-sample of 10 qualitative studies were independently rated using the RATS guidelines by a second rater (ML). The mean score from rating 1 was 14.8 and from rating 2 was 15.1, with a mean difference in ratings of 0.3 indicating acceptable concordance. The Effective Public Health Practice Project (EPHPP)[12] quality assessment tool for quantitative studies was used to rate the two quantitative studies. Independent ratings were made by two reviewers (VB, ML) of Ellis and King[13] and Resnick and colleagues[14], who agreed on rating both papers as moderate.

Data Analysis

The Conceptual Framework was developed using a modified narrative synthesis approach15. The three stages of the narrative synthesis comprised: 1) Developing a preliminary synthesis; 2) Exploring relationships within and between studies; and 3) Assessing the robustness of the synthesis. For clarity, the development of the Conceptual Framework (Stages 1 and 3) is presented in the Results before the sub-group comparison (Stage 2).

Stage 1: Developing a preliminary synthesis

A preliminary synthesis was developed using tabulation, translating data through thematic analysis of good quality primary data, and vote counting of emergent themes. For each included paper, the following data were extracted and tabulated: type of paper, methodological approach, participant information and inclusion criteria, study location, and summary of main study findings. An initial coding framework was developed and used to thematically analyse a sub-sample of qualitative research studies with the highest RATS quality rating (*i.e.* RATS score of 15 or above), using NVIVO QSR International qualitative analysis software (Version 8). The main over-arching themes and related sub-themes occurring across the tabulated data were identified, using inductive, open coding techniques. Additional codes were created by all analysts where needed and these new codes were regularly merged with the NVIVO master copy and then this copy was shared with other analysts, so all new codes were applied to the entire sub-sample.

Finally, once the themes had been created, vote counting was used to identify the frequency with which themes appeared in all of the 97 included papers. The vote count for each category comprised the number of papers mentioning either the category itself or a subordinate category. On completion of the thematic analysis and vote counting, the draft Conceptual Framework was discussed and refined by all authors. Some new categories were created, and others were subsumed within existing categories, given less prominence or deleted. This process produced the preliminary Conceptual Framework.

Stage 2: Exploring relationships within and between studies

Papers were identified from the full review which reported data from people from Black and Minority Ethnic (BME) backgrounds. These papers were thematically analysed separately, and the emergent themes compared to the preliminary Conceptual Framework. The thematic analysis utilised a more fine-grained approach, in which a 2nd analyst (VB) went through the papers in a detailed and line-by-line manner. The aim of the sub-group analysis was to specifically identify any additional themes as well as any difference in emphasis placed on

areas of the preliminary framework. The aim was to identify areas of different emphasis in this sub-group of studies, rather than being a validity check.

Stage 3: Assessing robustness of the synthesis

Two approaches were used to assess the robustness of the synthesis. First, qualitative studies which were rated as moderate quality on the RATS scale (*i.e.* RATS score of 14) were thematically analysed until category saturation was achieved. The resulting themes were then compared with the preliminary Conceptual Framework developed in Stages 1 & 2. Second, the preliminary Conceptual Framework was sent to an expert consultation panel. The panel comprised 54 advisory committee members of the REFOCUS Programme (see researchintorecovery.com for further details) who had either academic, clinical or personal expertise about recovery. They were asked to comment on the positioning of concepts within different hierarchical levels of the Conceptual Framework, identify any important areas of recovery which they felt had been omitted and make any general observations. The preliminary Conceptual Framework was modified in response to these comments, to produce the final Conceptual Framework.

Results

The flow diagram for the 97 included papers is shown in Figure 1.

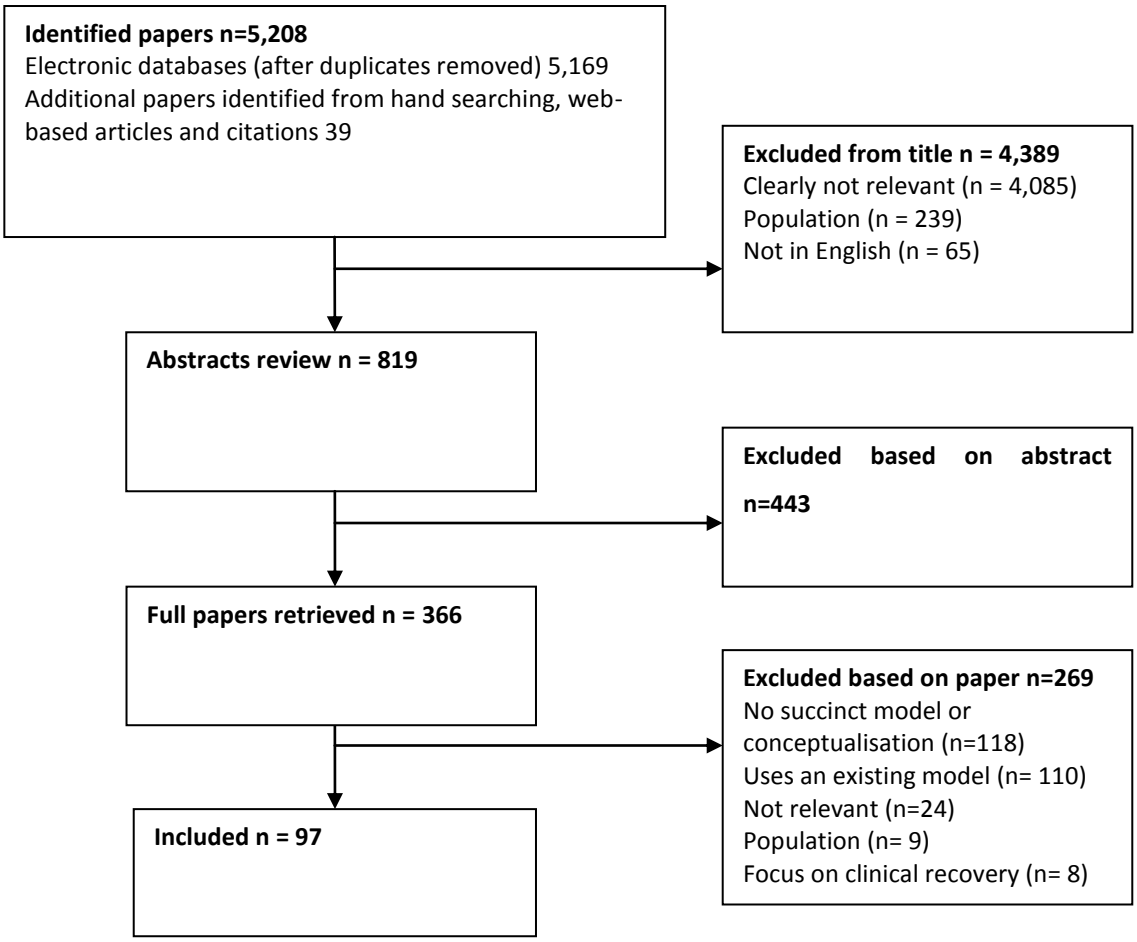

Figure 1: Flow chart to show assessment of eligibility of identified studies

The 97 included papers are shown in an Online Data Supplement 1.

The 97 papers comprised qualitative studies (n=37), narrative literature reviews (n=20), book chapters (n=7), consultation documents reporting the use of consensus methods (n=5), opinion pieces or editorials (n=5), quantitative studies (n=2), combining of a narrative literature review with personal opinion or where there is insufficient information on method for a judgement to be made (n=11), and elaborations of other identified papers (n=10). In summary, 87 distinct studies were identified. The ten elaborating papers were included in the thematic analysis but not the vote counting (included papers 11, 15, 16, 19, 26, 48, 50, 53, 71 and 73 shown in Online Data Supplement 1).

The 97 papers described studies conducted in 13 countries, including the United States of America (n=50), United Kingdom (n=20), Australia (n=8) and Canada (n=6). Participants were recruited from a range of settings including community mental health teams and facilities, self help groups, consumer-operated mental health services and supported housing facilities. The

majority of studies used inclusion criteria that covered any diagnosis of severe mental illness. A few studies only included participants who had been diagnosed with a specific mental illness (e.g. schizophrenia, depression). The sample sizes in qualitative data papers ranged from 4 to 90 participants, with a mean sample size of 27. The sample sizes in the two quantitative papers were 19 (pilot study of 15 service users and 4 case managers using a recovery interventions questionnaire[13]) and 1,076 (representative survey of people with schizophrenia[14]). The former was a pilot study of 15 service users with experience of psychotic illness and 4 case managers using a Recovery Interventions Questionnaire, carried out in Australia. The latter study analysed data from two sources, the Schizophrenia Patient Outcomes Research Team (PORT) client survey, which examined usual care in a random sample of people with schizophrenia in two US states and an extension to this survey which provided a comparison group.

There were various approaches to determining the stage of recovery of participants. Most studies rated stage of recovery using criteria such as: i) the person defined themselves as 'being in recovery'; ii) not hospitalised during the previous 12 months, iii) relatively well and symptom free; iv) providing peer support to others; or v) working or living in semi-independent settings. Only a few studies specifically used professional opinion - clinical judgement or scores on clinical assessments - about whether people were recovered.

The mean RATS score for the 36 qualitative studies was 14.9 (range 8 to 20). One qualitative study was not rated using the RATS guidelines because there was insufficient information on methodology within this paper. A RATS score of 15 or above, indicating high quality was obtained by 16 papers and used to develop a preliminary synthesis. A RATS score of 14, indicating moderate quality, was obtained by five papers. Independent ratings were made of the two quantitative papers, Ellis and King[13] and Resnick and colleagues[14] which were rated as moderate by two reviewers (VB + ML). Given this quality assessment, no greater weight was put on the quantitative studies in developing the category structure.

Conceptual Framework for Personal Recovery

A preliminary Conceptual Framework was developed, which comprised five superordinate categories: Values of recovery, Beliefs about recovery, Recovery-promoting attitudes of staff, Constituent processes of recovery, and Stages of recovery.

The robustness of the synthesis underpinning the preliminary Conceptual Framework was assessed in two steps; by re-analysing a sub-sample of qualitative studies and through expert consultation.

Sub-sample re-analysis

In addition to the higher quality qualitative studies analysed in the preliminary synthesis stage, an additional five moderate quality (RATS score of 14) qualitative studies were analysed, which confirmed that category saturation had been achieved, indicating that the categories are robust.

Expert consultation

A response was received from 23 (43%) of the 54 consulted experts with international and national academic, clinical, and/or personal expertise and experiences of recovery, who are advisory committee members of the REFOCUS programme into recovery. Responses were themed under the following headings: Conceptual (dangers of reductionism, separating processes from stages, confusing critical impetus for behaviours with actual behaviour, limitations of stage models); Structural (complete omissions, lack or over-emphasis upon specific areas of recovery), Language (too technical); and Bias (potential geographical bias). In response to this consultation, the preliminary Conceptual Framework was simplified, so the final Conceptual Framework now has three rather than five superordinate categories. Some sub-categories were re-positioned within Recovery Processes, and some category headings changed. Some responses identified areas of omission, such as the role of past trauma, hurt, and physical health in recovery. However, no alteration was made to the Conceptual Framework as these did not emerge from the thematic analysis. Other points around the strengths and limitations of the framework are addressed in the Discussion. Overall, the expert consultation process provided a validity check on content of Conceptual Framework, whilst we were careful to not to make radical changes which would have been unjustified, given the weight of evidence provided from preliminary analysis of the included papers.

The final Conceptual Framework comprises three inter-linked, superordinate categories: Characteristics of the Recovery Journey; Recovery Processes; and Recovery Stages.

Characteristics of the Recovery Journey were identified in all 87 studies, and vote-counting was used to indicate their frequency, shown in Table 1.

Table 1 Characteristics of the recovery journey

Characteristics	Number (%) of 87 studies identifying the characteristics
Recovery is an active process	44 (50)
Individual and unique process	25 (29)
Non-linear process	21 (24)
Recovery as a journey	17 (20)
Recovery as stages or phases	15 (17)
Recovery as a struggle	14 (16)
Multidimensional process	13 (15)
Recovery is a gradual process	13 (15)
Recovery as a life-changing experience	11 (13)
Recovery without cure	9 (10)
Recovery is aided by supportive and healing environment	6 (7)
Recovery can occur without professional intervention	6 (7)
Trial and error process	6 (7)

The categories of Recovery Processes and their vote counts, indicating frequency of the process being identified, for the two highest category levels are shown in Table 2.

Table 2 Recovery processes

Recovery processes	Number (%) of 87 studies identifying the process
Category 1: Connectedness	75 (86)
Peer support and support groups	39 (45)
Relationships	33 (38)
Support from others	53 (61)
Being part of the community	35 (40)
Category 2: Hope and optimism about the future	69 (79)
Belief in possibility of recovery	30 (34)
Motivation to change	15 (17)
Hope-inspiring relationships	12 (14)
Positive thinking and valuing success	10 (11)

Recovery processes	Number (%) of 87 studies identifying the process
Having dreams and aspirations	7 (8)
Category 3: Identity	65 (75)
Dimensions of identity	8 (9)
Rebuilding/redefining positive sense of identity	57 (66)
Overcoming stigma	40 (46)
Category 4: Meaning in life	59 (66)
Meaning of mental illness experiences	30 (34)
Spirituality	6 (41)
Quality of life	57 (65)
Meaningful life and social roles	40 (46)
Meaningful life and social goals	15 (17)
Rebuilding life	19 (22)
Category 5: Empowerment	79 (91)
Personal responsibility	79 (91)
Control over life	78 (90)
Focusing upon strengths	14 (16)

The full description of Recovery Processes categories and the vote counting results are shown in Online Data Supplement 2.

Fifteen studies developed Recovery Stage models. The studies were organised using the Transtheoretical Model of Change[1], as shown in Table 3.

Table 3: Recovery stages mapped on to Transtheoretical Model of Change

Online Data Supplement Study Number	Precontemplation	Contemplation	Preparation	Action	Maintenance & Growth
32		Novitiate recovery: Struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
73	Stuck	Accepting help	Believing	Learning	Self-reliant

Online Data Supplement Study Number	Precontemplation	Contemplation	Preparation	Action	Maintenance & Growth
3	Descent into hell	Igniting a spark of hope	Developing insight/ Activating instinct to fight back	Discovering keys to wellbeing	Maintaining equilibrium between internal and external forces
44	Demoralisation		Developing & establishing independence		Efforts towards community integration
36	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
14	Dependent/unaware	Dependent/aware		Independent/aware	Interdependent/aware
29	Moratorium	Awareness	Preparation	Rebuilding	Growth
78		Glimpses of recovery	Turning points	Road to recovery	
61		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
40	Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability
35	Initiating recovery			Regaining what was lost/moving forward	Improving quality of life
59	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
43		Turning point	Determination		Self-esteem

Recovery in Black and Minority Ethnic (BME) individuals

As part of stage two of the narrative synthesis process, six studies of recovery from the perspective of BME individuals were identified within the 87 studies. These six studies were re-analysed by a second analyst (VB), using a more fine-grained, line-by-line approach to thematic analysis. These comprised a survey of 50 recipients of a community development project in Scotland[16], a qualitative interview study of African-Americans[17], a narrative literature review[18], a qualitative study of 40 Maori and non-Maori New Zealanders[19], a pilot study to test whether the Recovery Star measure was applicable to Black and Asian Ethnic

Minority population[20] and a mixed method study of 91 males from African-Caribbean backgrounds[21]. These papers provide some preliminary insights into a small number of distinct ethnic minority perspectives, which do not represent a culturally homogenous group, although some similarities in experience can be observed. Although these six papers were included in the vote counting process, four of the six BME papers[16-18;20] were not used in the first stage thematic analysis. The line-by-line secondary analysis allowed us to explore in greater detail any differences in emphasis and additional themes present in these papers.

The main finding of the sub-group analysis indicated that there was substantial similarity between studies focusing on minority communities and those focusing on majority populations. All of the themes of the Conceptual Framework were present in all six of the BME papers. Despite this overall similarity, there was a greater emphasis in the BME papers on two areas in the Recovery Processes: Spirituality and Stigma; and two additional categories: Culturally specific factors; and Collectivist notions of recovery.

In relation to **Spirituality**, being part of a faith community and having a religious affiliation was seen as an important component of an individual's recovery. People from ethnic minorities more often described spirituality in terms of religion and a belief in God as a higher power, whereas the non-BME studies tended to conceptualise spirituality as encompassing a wider range of beliefs and activities.

In relation to **Stigma**, BME studies emphasised the stigma associated with race, culture and ethnicity, in addition to the stigma associated with having a mental illness. Furthermore, being an individual from a minority ethnic group seemed to accentuate the stigma of mental illness, as the person often viewed themselves as belonging to multiple stigmatised and disadvantaged groups. Individuals from ethnic minorities saw themselves as recovering from racial discrimination, stigma and violence, and not just from a period of mental illness.

The new category of **Culturally specific factors** included the use of traditional therapies, faith healers and belonging to a particular cultural group or community. Finally, **collectivist notions of recovery** were emphasised as both positive and negative factors. Many individuals discussed the hope and support they received from their collectivist identity, but for others the community added to the pressures of mental illness. This was particularly true where communities lacked information and awareness regarding mental illness. Furthermore, the

negative impact of the community was felt not only at the level of the individual, but also at the collectivist level, with the whole family being adversely affected by stigma.

Discussion

This is the first systematic review and narrative synthesis of personal recovery. A Conceptual Framework was developed using a narrative synthesis which identified three superordinate categories: Characteristics of the Recovery Journey, Recovery Processes and Recovery Stages. For each superordinate category, key dimensions were synthesised. The Recovery Processes, which have the most proximal relevance to clinical research and practice, can be summarised using the acronym CHIME. The robustness of the category structure was enhanced by the systematic nature of the review, the quality assessment of included studies, the category saturation reached in the analysis, and the content validity of the expert consultation. Heterogeneity between studies was explored descriptively. A sub-group comparison between the experiences of recovery from the perspective of BME individuals identified similar themes, with a greater emphasis on Spirituality and, Stigma, and two additional themes: Culturally specific factors, and Collectivist notions of recovery.

Implications for research and practice

Key knowledge gaps have been identified as the need for clarity about the underpinning philosophy of recovery[22], better understanding of the stages and processes of recovery[6], and valid measurement tools[23]. This study can inform each of these gaps.

Recovery has been conceptualised as a vision, a philosophy, a process, an attitude, a life orientation, an outcome and a set of outcomes[6]. This has led to the concern that "*its scope can make a cow-catcher on the front of a road train look discriminating*"[24]. An empirically-based Conceptual Framework can bring some order to this potential chaos. Characteristics of the Recovery Journey provide conceptual clarity about the philosophy. Recovery Processes can be understood as measurable dimensions of change which typically occur during recovery, and provide a taxonomy of recovery outcomes[25]. Finally, Recovery Stages provide a framework for guiding stage-specific clinical interventions and evaluation strategies.

The framework contributes to understanding about stages and processes of recovery in two ways. First, it allows available evidence to be more easily identified. A recovery orientation has overlap with the literature on wellbeing[26], positive psychology[27] and self-management[28], and systematic reviewing is hampered by the absence of relevant MeSH (Medical Sub-

Headings) headings relating to recovery concepts. The coding framework provides key-words for use when undertaking secondary research, and the identification of related terms provides a taxonomy which will be useable in reviews.

Second, the framework provides a structure around which research and clinical efforts can be orientated. The relative contribution of each Recovery Process, investigating interventions which can support these processes, and the synchrony between recovery processes and stages are all testable research questions. For clinical practice, the CHIME recovery processes support reflective practice. If the goal of mental health professionals is to support recovery then one possible way forward is for each Working Practice to be evaluated in relation to its impact on these processes. This has the potential to contribute to current debates about recovery and, for example, assertive outreach[29], risk[30] and community psychiatry[31].

Finally, the Conceptual Framework can contribute to the development of measures of personal recovery. Compendia of existing measures have been developed[32;33], showing that the conceptual basis of measures is diverse. The Conceptual Framework provides a foundation for developing standardised recovery measures, and is the basis for a new measure currently being developed by the authors to evaluate the contribution of mental health services to an individual's recovery. The challenge will then be to incorporate a focus on recovery outcomes, and associated concepts such as wellbeing[27]**,** into routine clinical practice[34]**.**

Limitations

The study has three methodological and two conceptual limitations. The first methodological limitation is that the narrative synthesis approach was modified, and could have been widened. For example, the exploration in Stage 2 of relationships between studies could have considered the sub-group of studies which had higher levels of consumer involvement in their design, but it proved impossible to reliably rate identified studies in this dimension. The second technical limitation is that the emergent categories were only one way of grouping the findings, and the categories changed as a result of expert consultation. In particular, the three superordinate categories are not separate, since processes clearly occur within the identified stages, and the characteristics of recovery describe an overall movement through stages of recovery. Our categorical separation brings structure, but a replication study may not arrive at the same overall thematic structure. The final technical limitation is that analysis synthesised the interpretation in the paper of the primary data in each paper, rather than considering the

primary data directly. Future research could compare papers generated by different stakeholder groups, such as consumer researchers, clinical researchers, and policy-makers.

The first conceptual limitation is that this review, whilst synthesising the current literature on personal recovery, should not be seen as definitive. A key scientific challenge is that the philosophy of recovery gives primacy to individual experience and meaning ('idiographic' knowledge), whereas mental health systems and current dominant scientific paradigms give prominence to group-level aggregated data ('nomothetic' knowledge)[5]. The practical impact is that current recovery research is primarily focused at the bottom of the hierarchy of evidence[35]. This was our finding, with qualitative, case study and expert opinion methodologies dominating. A motivator for the current study was to provide evidence of the form viewed as high quality within the current scientific paradigm, but several of our expert consultants highlighted the dangers of closing down discourse. Since recovery is individual, idiosyncratic and complex, this review is not intended to be a rigid model of what recovery 'is'. Rather, it is better understood as a resource to inform future research and clinical practice. The second conceptual limitation relates to the sub-group analysis looking at papers focusing on non-majority populations. Due to a lack of research, it was not possible to look at the experience and perspectives of individuals from different minority groups. Therefore, the BME sub-group represents a heterogeneous and incredibly diverse set of populations. However, it was felt that all the populations included in these papers, shared a common experience of belonging to minority ethnic group, and that this experience may have important implications to the meaning of personal recovery, and to the experience of mental health services in general. The lack of data coupled with the areas of difference found in the present review, highlights a need for further work to be conducted with people from minority ethnic communities.

Future research

This systematic review and narrative synthesis has highlighted the dominance of recovery literature emanating from USA. Culturally, the USA neglects character strengths such as patient and tolerance[36], and favours individualistic over collectivist understandings of identity. Although there were very few studies which looked at recovery experiences of individuals from BME backgrounds, the sub-sample of BME studies indicated that there are important differences in emphasis. There is a need for research to be conducted using a more diverse samples of people from different ethnic and cultural backgrounds, at differing stages of recovery and experiencing different types of mental illness.

The complexity of personal recovery requires a range of theoretical inquiry positions. This review focused on research into first-person accounts of recovery, where individual meanings of recovery have dominated. This has led to a framework which may under-emphasise the importance of the wider socio-environmental context, including important aspects such as stigma and discrimination. Viewing recovery within an ecological framework, as suggested by Onken and colleague[35], encompasses an individual's life context (characteristics of the individual, such as hope and identity) as well as environmental factors (such as opportunities for employment and community integration) and the interaction between the two (such as choice). A more complete understanding of recovery requires greater attention to all these levels of understanding, for instance, upon how power is related to characteristics of individuals or groups (e.g. race and culture), how clinicians and patients interact within different stages of recovery and how these interactions change over time. There is also a need for future research to increase our understanding of how subtle micro-processes of recovery are operating, such as how hope is reawakened and sustained.

Supporting Recovery Processes may be the future mental health research priority. The 13 dimensions identified as Characteristics of the Recovery Journey capture much of the experience and complexities of recovery, and further research may not have a high scientific pay-off. Similarly, although the Recovery Stages could be mapped onto the Transtheoretical Model of Change[1], there was little consensus about the number of recovery phases. It may therefore be more helpful to undertake evaluative research addressing specific service-level questions (such as whether people using a service are making recovery gains over time[37] or in different service settings[38]), rather than further studies seeking conceptual clarity. Overall, the emergent priority is the development and evaluation of interventions to support the five CHIME Recovery Processes. The subordinate categories point to the need for a greater emphasis on assessment of strengths and support for self-narrative development, a new construction of the contribution of the mental health system being as much about developing inclusive communities and enabling access to peer support as providing treatments, and clinical interaction styles which promote empowerment and self-management. The CHIME categories are potential clinical end-points for interventions, in contrast with the current dominance of clinical recovery end-points such as symptomatology or hospitalisation rates. They also provide a framework for empirical investigation of the relationship between recovery outcomes, using methodologies developed in relation to clinical outcomes[39]. This

area of enquiry is currently small[40] but an important priority if potential trade-offs between desirable outcomes are to be identified[41].

Orienting mental health services towards recovery will involve system transformation[42]. The research challenge is to develop an evidence base which simultaneously helps mental health professionals to support recovery and respects the understanding that recovery is a unique and individual experience rather than something the mental health system does to a person. This Conceptual Framework for personal recovery, which has been developed through a systematic review and narrative synthesis, provides a useful starting point for meeting this challenge.

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(40) Andresen R, Caputi P, Oades L. Do clinical outcome measures assess consumer-defined recovery? Psychiatry Research 2010; 177:309-317.

(41) Slade M, Hayward M. Recovery, psychosis and psychiatry: research is better than rhetoric. Acta Psychiatr Scand 2007; 116(2):81-83.

(42) Shepherd G, Boardman J, Burns M. Implementing Recovery. A methodology for organisation change. London: Sainsbury Centre for Mental Health; 2010.

Online Data Supplement 1

Included Studies (n=97)

	Full reference	Country	Method	Quality rating
1	Provencher H, Gregg R, Mead S, Mueser K. The role of work in the recovery of persons with psychiatric disabilities, *Psychiatr Rehab. J*, 2002, **26**(2), 132-144.	USA	Semi-structured individual interviews (n=14 participants with psychiatric disabilities)	13/25
2	Kelly M, Gamble C. Exploring the concept of recovery in schizophrenia, *J Psychiatr Ment Health Nurs.* 2005 Aug;**12**(4):386.	Unclear	Literature review	Not rated
3	Noiseux S, Ricard N. Recovery as perceived by people with schizophrenia, family members and health professionals: A grounded theory. *Int. J of Nurs. Studies*, 2008, **45** (8), 1148-1162	Canada	Semi-structured interviews and field notes (n=41 people with schizophrenia, family members and health professionals)	18/25
4	Social Care Institute for Excellence, A common purpose: Recovery in future mental health services, 2007.	UK	Literature review	Not rated
5	Schon UK, Denhov A, Topor A. Social relationships as a decisive factor in recovering from severe mental illness, *Int. J of Soc Psychiatry*, 2009, **55** (4) 336-347.	Sweden	Interviews (n=58 people who had recovered from serious mental illness)	13/25
6	Smith M. Recovery from severe psychiatric disability: Findings of a qualitative study, *Psychiatr Rehab. J*, 2000, **24** (2), 149-158	USA	Semi-structured interviews (n=10 participants with serious mental illness)	13/25
7	Tooth B, Kalyanasundaram V, Glover H, Momenzadah S. Factors consumers identify as important to recovery from schizophrenia, *Australasian Psychiatry*, 2003, **11**(1), 70-77.	Australia	Focus groups (n=57 people in recovery from schizophrenia)	12/25
8	Libermann R, Kopelowicz A, Ventura J, Gutkind D. Operational criteria and factors related to recovery from schizophrenia, *Int. Review of Psychiatry*, 2002a.**14**(4), 256-272.	USA	Literature review, focus groups, case vignettes of people recovering from schizophrenia	Not rated
9	Ramon S, Healy B, Renouf N. Recovery from Mental Illness as an Emergent Concept and Practice in Australia and the UK, *Int.. J. Soc Psychiatry*, **53**, 108-122.	UK and Australia	Literature review	Not rated
10	Mancini MA. A qualitative analysis of turning points in the recovery process, *American J of Psychiatr Rehab.*, 2007, **10**(3), 223-244.	USA	Semi-structured interviews (n=16 participants recovering from serious psychiatric disability)	13/25
11	Mezzina R, Davidson L, Borg M, Marin I, Topor A, Sells D. The social nature of recovery: Discussion and implications for practice, American J of Psychiatr Rehab.. 2006, 9(1), 63-80.	Italy and USA	Literature review and conceptual paper	Not rated

12	Fallot R. Spiritual and religious dimensions of mental illness recovery narratives, *New directions for mental health services*, **80**, Winter, 1998.	Unclear	Personal narratives and literature review	Not rated
13	Morse G. On being homeless and mentally ill: A multitude of losses and the possibility of recovery, chapter 16, in Harvey J & Miller E (Eds). *Loss and trauma: General and close relationship perspectives*. New York, US: Brunner-Routledge, 2000	Unclear	Personal narratives and literature review	Not rated
14	*Emerging best practices in mental health recovery,* National Institute for Mental Health in England., Great Britain. National Health Service, 2004.	UK	Based on Ohio Department of Mental Health work on the meaning and process of recovery.	Not rated
15	Piat M, Sabetti J, Couture A, Sylvestre J, Provencher H, Botschner J, Stayner D. What does recovery mean for me? Perspectives of Canadian mental health consumers, *Psychiatr Rehab. J*, 2009, **32**(3), 199-207.	Canada	Qualitative interviews (n= 60 consumers of mental health services)	18/25
16	Davidson L, O'Connell M, Staeheli M, Weingarten R, Tondora J, Evans A. Concepts of recovery in Behavioral health: History, review of the evidence, and critique, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M, *A practical guide to recovery-orientated practice*. Oxford. Oxford University Press, 2009.	USA	Literature review	Not rated
17	Diamond R. Recovery from a psychiatrist's viewpoint, *Postgraduate Medicine*, 2006, **Sept.** Special, 54-62	Unclear	Literature review	Not rated
18	Gagne C, White W, Anthony W. Recovery: A common Vision for the fields of mental health and addiction, *Psychiatr Rehab. J*, 2007, **31**(1), 32-37.	USA	Literature review	Not rated
19	Davidson L, O'Connell M, Tondora J, Lawless M, Evans A. Recovery in Serious Mental Illness: A New Wine or Just a New Bottle? *Professional Psychology: Research and Practice*, **36** (5), 480-487	USA	Literature review and concept map	Not rated
20	Davidson L, O'Connell M, Staeheli M, Weingarten R, Tondora J, Evans A A model of being in recovery as a foundation for recovery-orientated practice, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M *A practical guide to recovery-orientated practice*. Oxford. Oxford University Press, 2009.	USA	Interviews (n=100 consumers and people who have lived with mental illness)	Not rated
21	Slade M. 'Recovery-focused mental health services: The personal recovery framework', in *Personal recovery and mental illness: A guide for mental health professionals*, Cambridge University Press, 2009.	UK	Literature review	Not rated
22	Repper J, Perkins R. 'The individual's recovery journey: towards a model for mental health practice, in Repper, J. & Perkins, R. *Social inclusion and recovery: a model for mental health practice*, Bailliere Tindall, 2003.	UK	Literature review	Not rated
23	Markowitz FE. Sociological Models of Recovery, chapter 4, in Ralph, R. & Corrigan, P. *Recovery in mental illness: Broadening our understanding of*	USA	Literature review	Quality not

	wellness. Washington, DC, US: American Psychological Association, 2005.			assessed
24	Ralph R. Verbal Definitions and Visual Models of Recovery: Focus on the Recovery Model, in Ralph R, Corrigan P. *Recovery in Mental illness: Broadening our understanding and wellness*, Washington, DC, US: American Psychological Association, 2005.	USA	Literature review	Not rated
25	Libermann RP, Kopelowicz A. Recovery from schizophrenia: A challenge for the 21st century, *Int. Review of Psychiatry*, 2002, 14(4) 245-255.	USA	Literature review	Not rated
26	Libermann R, Kopelowicz A. Open forum. Recovery from schizophrenia: a concept in search of research, *Psychiatr Services*, 2005, **56**(6), 735-742	USA	Literature review	Not rated
27	Whitehorn D, Brown J, Richard J, Rui Q, Kopala L Multiple dimensions of recovery in early psychosis, Int. Review of Psychiatry, 2002, 14(4), 273-283.	Canada	Literature review	Not rated
28	Ellis G, King R. Recovery focused interventions: Perceptions of mental health consumers and their case managers. *Australian e-J for the Advancement of Ment. Health*, 2003, **2**(2).	Australia	Literature review and piloting of a consumer and case manager questionnaire	Not rated
29	Andresen R, Oades L, Caputi P. The experience of recovery from schizophrenia: towards an empirically validated stage model, *Australian & New Zealand J of Psychiatry*, 2003, **37**(5), 586-594.	Australia	Literature review and qualitative analysis	Not rated
30	Torrey W, Wyzik, P. The recovery vision as a service improvement guide for community mental health center providers. *Community Ment. Health J*, 2000, **36** (2):209-216.	USA	Opinion piece	Not rated
31	Cleary A, Dowling M. The road to recovery, *Ment. Health Practice*, 2009, **12**(5), 28-31.	Ireland	Literature review	Not rated
32	Song L-Y, Shih C-Y. Factors, process and outcome of recovery from psychiatric disability the utility model, *Int. J of Social Psychiatry*, 2009, **55**(4), 348-360.	Taiwan	Qualitative interviews (n=15 consumers in recovery and their caregivers)	15/25
33	Resnick S, Fontana A, Lehman A, Rosenheck R. An empirical conceptualization of the recovery orientation, *Schizophrenia Research*, 2005, **75**, 119-128.	USA	Survey on the treatment of schizophrenia (n=1,076)	Not rated
34	Jacobson N. Experiencing recovery: A dimensional analysis of recovery narratives, *Psychiatr Rehab. J* 2001 Winter; **24**(3):248-56.	USA	Dimensional analysis of 30 narratives of recovery.	Not rated
35	Young S, Ensing D. Exploring recovery from the perspective of people with psychiatric disabilities, *Psychiatr Rehab. J*, 1999, **22**(3), 219-231.	USA	Semi-structured interviews (n= 18 people with psychiatric disabilities) and focus groups (n=2, 11 participants in total)	15/25
36	Merryman M, Riegel S. The recovery process and people with serious mental illness living in the community: An occupational therapy perspective, *Occupational Therapy in Ment. Health*. 2007, **23**(2), 51-73.	USA	Interviews (n=20 service users)	16/25
37	Ralph R. Recovery, *Psychiatr Rehab. Skills*, 2000, **4**(3), 480-517.	USA	Literature review	Not rated

38	Jensen L, Wadkins T. Mental health success stories: finding paths to recovery, *Issues in Ment. Health Nurs.*, 2007, **28**(4), 325-340.	USA	Semi-structured interviews (n=20 service users)	13/25
39	Schrank B, Slade M. Recovery in psychiatry, *Psychiatr Bulletin*, 2007, **31**(9), 321-325.	Austria, UK	Literature review	Not rated
40	Spaniol S, Wewiorski N, Gagne C, Anthony W. The process of recovery from schizophrenia, *Int. review of psychiatry*, 2002, **14**, 327-336.	USA	Interviews (n=12 consumers, conducted every four to eight months, over a 4 year period)	16/25
41	Mental Health Recovery Study Working group, *Mental Health 'Recovery': users and refusers. What do psychiatric survivors in Toronto think about Mental Health Recovery*? Wellesley Institute, 2009.	Canada	Community-based participatory research approach., focus groups (n=7)	Not rated
42	Hopper K. Rethinking social recovery in schizophrenia: what a capabilities approach might offer, *Social Science and Medicine*, 2007, **65**(5), 868-879.	USA	Literature review	Not rated
43	Peden A. Recovering in depressed women: research with Peplau's theory. *Nurs Sci Q*, 1993, **6**(3), 140-146	USA	Semi-structured interviews (n= 7 participants recovering from depression)	14/25
44	Bradshaw W, Armour M, Roseborough D. Finding a place in the World: The experience of Recovery from Severe Mental Illness, Qual. Social Work, 2007, 6(1), 27-47. Sage Publications, UK.	USA	Semi-structured interviews (n= 45 with severe mental illness, conducted over 3 years)	18/25
45	Sung K, Kim S, Puskar K, Kim E. Comparing Life Experiences of College Students with Differing Courses of Schizophrenia in Korea: Case Studies Perspectives in Psychiatric Care, 2006, 42(2), 82-94.	South Korea	In-depth interviews (n= 8 people diagnosed with schizophrenia)	17/25
46	NHS Scotland, Finding strength from within, Report on three local projects looking at mental health and recovery with people from some of black and minority ethnic communities in Edinburgh, 2008.	Scotland	Exploratory community development project (n= 50 people from BME communities with personal experience of recovery)	Not rated
47	Ajayi S, Billsborough J, Bowyer T, Brown P, Hicks A, Larsen J, Mailey P, Sayers R, Smith R. Getting back into the world: Reflections on lived experiences of recovery, *Rethink recovery series: 2.,* 2009.	UK	Interviews (n=48 people with personal experience of mental illness)	18/25
48	Connecticut Department of Mental Health Addiction Services: Proposed model of mental health recovery and recovery-orientated services, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M, *A practical guide to recovery-orientated practice*. Oxford. Oxford University Press, 2009.	USA	Position paper	Not rated
49	Mancini A. Self-determination theory: A framework for the recovery paradigm, *Adv. in Psychiatr Treatment*.2008, 14(5),358-365.	USA	Literature review	Not rated
50	Armour M, Bradshaw W. Roseborough D. African Americans and recovery from severe mental illness, *Social Work in Ment. Health*, 2009, **7(**6), 602-622.	USA	Semi-structured interviews (n=9 African-American with serious and persistent mental illness, conducted with each	11/25

			participant 3 times)	
51	Davidson L, Andres-Hyman R, Bedregal L, Tondora J, Fry J, Kirk T. From 'Double trouble to Dual recovery': Integrating models of recovery in addiction and mental health, *J of Dual Diagnosis*, **4**(3), 2008, 273-290.	USA	Literature review and consultation (n=45 people with addictions or in recovery from serious mental illness.	8/25
52	Sullivan W. A long and winding road: The process of recovery from severe mental illness, in Spaniol L, Gagne C, Koehler M, (eds) *Psychological and social aspects of Psychiatr disabilities*, Boston University Center, 1997.	USA	Semi-structured interviews (n=46 current and former service users)	13/25
53	Mancini M. Consumer-providers' theories about recovery from serious psychiatric disabilities, chapter 2, from Rosenberg, Community Mental Health: Challenges for the 21st Century, Routledge, 2006.	USA	Semi-structured interviews (n==15 people diagnosed with a psychiatric disability who also provide peer-support services to others)	11/25
54	Ridge D, Ziebland S. "The old me could never have done that": how people give meaning to recovery following depression, Qual. Health Research, 2006, 16(8), 1038-1053.	UK	Open-ended interviews (n=38 people who have had depression)	CHECK RATS
55	Sydney West Area Health Service, (2008) Maintaining wellness and promoting recovery, sections 4-6, in *The wellness guide – a resource to support the recovery journey*, March 2008.	Australia	Part of a Wellness Guide developed in partnership between consumers and clinicians.	
56	Armstrong N, Steffen J. The Recovery Promotion Fidelity Scale: Assessing the organizational promotion of recovery, *Community Ment. Health J*, 2009, **4**5(3), 163-170.	USA	Literature review and concept mapping (n= 5 focus groups) and survey	16/25
57	Noordsy D, Toeey W, Mueser K, O'Keefe C, Fox L. Recovery from severe mental illness: an intrapersonal and functional outcome definition, *Int. Review of Psychiatry*, 2002, **14**, 318-326.	USA	Focus groups and observation	Not rated
58	Forchuk C, Jewell J, Tweedell D, Steinnage IL. Reconnecting the client experience of recovery from psychosis, *Perspectives in Psychiatr Care*, 2003, **39** (4) 141-150.	Canada	Interviews and observation (n=10 patients over the initial year of treatment with clozapine or risperidone)	16/25
59	Baxter E, Diehl S. Emotional stages: Consumers and family members recovering from the trauma of mental illness, *Psychiatr Rehab. J*, 1998, **21**(4), 349-355.	USA	Interviews (n=40 consumers)	11/25
60	Oades L, Deane F, Crowe T, Lambert W, Kavanagh D, Lloyd C. Collaborative recovery: An integrative model for working with individuals who experience chronic and recurring mental illness. *Australasian Psychiatry*, 2005, **13**(3), 279-284.	Australia	Multi-site study in 9 organisations	Not rated
61	Glover H. Lived experience perspectives, in *Handbook of psychosocial rehabilitation*, King R, Lloyd C, Meehan T, Wiley-Blackwell, 2007.	Australia	Literature review and personal narrative	Not rated
61	Ridgeway P. Re-Storying psychiatric disability: Learning from first person recovery narratives, *Psychiatr Rehab. J*, 2001, **24**(4), 335-343	USA	Grounded theory analysis of 4 existing 'seminal' narratives	17/25

63	Bonney S, Stickley T. Recovery and mental health: A review of the British literature, *J of Psychiatr and Ment. Health Nurs*., 2008, **15**(2), 140-153.	UK	Literature review	Not rated
64	Mead S, Copeland M. What recovery means to us: Consumers' perspectives, *Community Ment. Health J*, 2000, **36**(3), 315-328.	USA	Personal narratives and opinion piece	8/25
65	Sowers W. Transforming systems of care: the American Association of Community Psychiatrists guidelines for recovery orientated services, *Community Ment. Health J*, 2005, **41**(6), 757-774	USA	Literature review	Not rated
66	Plum K. How patients view recovery: what helps, what hinders, *Archives of Psychiatr Nurs.,* 1987, **1**(4), 285-293.	USA	Analysis of narratives (n=20)	13/25
67	Ahern L, Fisher D. Recovery at your own PACE (Personal Assistance in Community existence). *J of Psychosocial Nurs. & Ment. Health Services*, 2001, **39**(4), 22-32.	USA	Literature review and qualitative research	Not rated
68	Jacobson N, Curtis L. Recovery as policy in mental health services: Strategies emerging from the states, *Psychiatr Rehab. J*, 2000, **23**(4), 333-341.	USA	Literature review	Not rated
69	Lunt A. A theory of recovery. *J of Psychosocial Nurs. & Ment. Health Services*, 2002, **40** (12), 32-39.	USA	Literature review and opinion piece	Not rated
70	Nicholls V. *Feeding the flowers: SPN perspective on recovery*, 2007.	UK	Literature review and qualitative research	Not rated
71	Ralph R, Risman J, Kidder, K. *The Maine contingent of the recovery advisory group*, May, 1999.	USA	Personal narratives and literature review	6/25
72	Mental Health Providers Forum, *The recovery star model*, 2008.	UK	Measure development	Not rated
73	Mental health providers forum, *The recovery star model and cultural competency*, BAME Pilot Report, 2009.	UK	Pilot study to test measure with BME population	Not rated
74	Brown M, Essien P, Etim-Ubah P et al. *Report of the community led research project focusing on male African and African Caribbean perspectives on recovery*, Southside Partnership Fanon, 2008.	UK	Semi-structured interviews and questionnaires (n=91)	20/25
75	Mancini M, Hardiman E, Lawson H. Making Sense of It All: Consumer Providers' Theories about Factors Facilitating and Impeding Recovery from Psychiatric Disabilities, *Psychiatr Rehab. J*, 2005, **29**(1), 48-55.	USA	Semi-structured interviews (n=15 adults recovering from serious psychiatric disability and leading consumer provision of mental health services)	14/25
76	Bradstreet S, Brown W. Elements of recovery: Int. learning and the Scottish context, *SRN Discussion Paper Series* Report **No. 1.** 2004.	UK	Literature review	Not rated
77	Jacobson N, Greenley D. (2001) What is recovery? A conceptual model and explication. *Psychiatr Services*, **52** (4), 482-485.	USA	Synthesis of consumer narratives	Not rated
78	Lapsley H, Waimarie Nikora L, Black R. *Kia Mauri Tau! Narratives of recovery from disabling mental health problems*. Report of the University of Waikato Mental	New Zealand	Interviews (n=40 who once had a disabling mental health problem)	20/25

	Health Narratives Project. Wellington: Mental Health Commission, 2002.			
79	Jenkins J, Carpenter-Song E. The new paradigm of recovery from schizophrenia: cultural conundrums of improvement without cure, *Culture, Medicine and Psychiatry*, 2006, **29**(4), 379-414.	USA	Interviews (n=90 people attending community out-patient clinics)	18/25
80	Barton R. The rehabilitation-recovery paradigm: A statement of philosophy for a public mental health system, *Psychiatr Rehab. Skills*, 1998, **2**(2), 171-187.	USA	Literature review	Not rated
81	Spaniol L, Gagne C, Koehler M. The recovery framework in rehabilitation and mental health, chapter 4, in Moxley, D. & Finch, J. *Sourcebook of rehabilitation and mental health practice*. New York, US: Kluwer Academic/Plenum, 2003.	USA	Literature review	Not rated
82	Glover H. Recovery based service delivery: Are we ready to transform the words into a paradigm shift? *Australian e-J for the Advancement of Ment. Health*, 2005, **4**(3), 1-4.	Australia	Opinion piece	Not rated
83	Irish Mental Health Commission. *A recovery approach within the Irish mental health services: A framework for development*, 2008.	Ireland	Literature review	Not rated
84	Ochocka J, Nelson G, Janzen R. Moving Forward: Negotiating Self and External Circumstances in Recovery, *Psychiatr Rehab. J*, 2005, **28**(4), 315-322.	Canada	In-depth interviews (n=28 people who had experienced serious mental health problems)	14/25
85	Brown W. The possibility of wellness, *Ment. Health Today*, 2007, **Sept.** 23-26.	Scotland	Semi-structured interviews (n=64)	12/25
86	Steen M. Essential structure and meaning of recovery from clinical depression for middle-adult women: a phenomenological study*, Issues in Ment. Health Nurs.*, 1996, **17**(2), 73-92.	USA	Interviews (n=22 participants with clinical, unipolar depression)	13/25
87	Fisher D. Healthcare reform based on an empowerment model of recovery by people with psychiatric disabilities, *Hospital and community psychiatry*, 1994, **45**(9), 913-915.	USA	Opinion paper	Not rated
88	Substance Abuse and Mental Health Service Administration, *National Consensus statement on mental health recovery*, 2004.	USA	Consensus methods (n= 110 expert panellists)	Not rated
89	Onken S, Craig C, Ridgway P, Ralph R, Cook J. An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatr Rehab. J*, **31**(1), 9-22. 2007	USA	Literature review	Not rated
90	Anthony W. Recovery from mental illness: The guiding vision of the mental health service system in the 1990s, *Psychosocial Rehab. J*, 1993, **16**(4), 11-23.	USA	Opinion piece and literature review	Not rated
91	Pitt L, Kilbride M, Nothard S, Welford M, Morrison A. Researching recovery from psychosis: a user-led project, *Psychiatr Bulletin*, 2007, **31**, 55 - 60.	UK	User-led interview study (n= 7 people in recovery)	19/25
92	Anderson B, Munchel W. *Opportunity on the doorstep: recovery-orientated leadership*, 2005 Village ISA and Community Activators, Inc.	USA	Opinion piece	Not rated

93	Borg M, Davidson, L. The nature of recovery as lived in everyday experience, *J of Ment. Health*, 2008, **17**(2), 129-140.	Norway	Interviews (n=13 individuals in recovery)	14/25
94	Asmundsdottir E. Creation of New Services: Collaboration Between Mental Health Consumers and Occupational Therapists, *Occupational Therapy in Ment. Health*, 2009, **25**(2), 115-126.	Iceland	Interviews and focus groups (n=25)	14/25
95	Davis E, Velleman R, Smith G, Drage M. Psychosocial developments: Towards a model of recovery, in Velleman R, Davies E, Smith G, & Drage M. (eds.) *Changing outcomes in Psychosis, Collaborative cases from practitioners, users and carers*, pp1-21., BPS Blackwell, 2006.	UK	Literature review	Not rated
96	Warren K. *Exploring the concept of recovery from the perspective of people with mental health problems*. Norwich School of Social Work and Psychosocial Studies, University of East Anglia, 2003.	UK	Literature review, narrative analysis, interviews	9/25
97	Piat M, Sabetti J, Bloom D. The importance of medication in consumer definitions of recovery from serious mental illness: A qualitative study, *Issues in Ment. health Nurs.*, 2009, **30**(8), 482-490.	Canada	Semi-structured interviews (n= 54 consumers of mental health services)	18/25

Online Data Supplement 2
Vote counting of Recovery Processes

Recovery Processes	Number (%) of 87 studies
Category 1: Connectedness	**75 (86%)**
1.1 Peer support and support groups	39 (45%)
1.1.1 Availability of peer support	22 (25%)
1.1.2 Becoming a peer support worker or advocate	17 (20%)
1.2 Relationships	33 (38%)
1.2.1 Building upon existing relationships	19 (22%)
1.2.2 Intimate relationships	9 (10%)
1.2.3 Establishing new relationships	8 (9%)
1.3 Support from others	53(61%)
1.3.1 Support from professionals	42 (48%)
1.3.2 Supportive people enabling the journey	27 (31%)
1.3.3 Family support	26 (30%)
1.3.4 Friends and peer support	18 (21%)
1.3.5 Active or practical support	4 (5%)
1.4 Being part of the community	35 (40%)
1.4.1 Contributing and giving back to the community	21 (24%)
1.4.2 Membership of community organisations	13 (15%)
1.4.3 Becoming an active citizen	11 (13%)
Category 2: Hope and optimism about the future	**69 (79%)**
2.1 Belief in possibility of recovery	30 (34%)
2.2 Motivation to change	15 (17%)
2.3 Hope-inspiring relationships	12 (14%)
2.3.1 Role-models	8 (9%)
2.3 Positive thinking and valuing success	10 (11%)
2.4 Having dreams and aspirations	7 (8%)
Category 3: Identity	**65 (75%)**
3.1 Dimensions of identity	8 (9%)
3.1.1 Culturally specific factors	7 (8%)
3.1.2 Sexual identity	2 (2%)
3.1.3 Ethnic identity	4 (5%)
3.1.4 Collectivist notions of identity	6 (7%)
3.2 Rebuilding/redefining positive sense of self	57 (66%)
3.2.1 Self-esteem	21 (24%)
3.2.2 Acceptance	21 (24%)
3.2.3 Self-confidence and self-belief	11 (13%)

3.3 Over-coming stigma	40 (46%)
3.3.1 Self-stigma	27 (31%)
3.3.2 Stigma at a societal level	32 (37%)
Category 4: Meaning in life	**59 (66%)**
4.1 Meaning of mental illness experiences	*30 (34%)*
4.1.1 Accepting or normalising the illness	22 (25%)
4.2 Spirituality (including development of spirituality)	*36 (41%)*
4.3 Quality of life	57 (65%)
4.3.1 Wellbeing	27 (31%)
4.3.2 Meeting basic needs	18 (21%)
4.3.3 Paid voluntary work or work related activities	19 (22%)
4.3.4 Recreational and leisure activities	8 (9%)
4.3.5 Education	7 (8%)
4.4 Meaningful social and life goals	15 (17%)
4.4.1 Active pursuit of previous or new life or social goals	15 (17%)
4.4.2 Identification of previous of new life or social goals	8 (9%)
4.5 Meaningful life and social roles	40 (46%)
4.5.1 Active pursuit of previous or new life or social roles	40 (46%)
4.5.2 Identification of previous of new life or social roles	34 (39%)
4.6 Rebuilding of life	20 (23%)
4.6.1 Resuming with daily activities and daily routine	12 (14%)
4.6.2 Developing new skills	8 (9%)
Category 5: Empowerment	**79 (91%)**
5.1 Personal responsibility	79 (91%)
5.1.1 Self-management	60 (69%)
Coping skills	25 (29%)
Managing symptoms	22 (25%)
Self-help	12 (14%)
Resilience	25 (29%)
Maintaining good physical health and wellbeing	12 (14%)
5.1.2 Positive risk-taking	17 (20%)
5.2 Control over life	78 (90%)
5.2.1 Choice	31 (36%)
Knowledge about illness	17 (20%)
Knowledge about treatments	7 (8%)
5.2.2 Regaining independence and autonomy	23 (26%)
5.2.3 Involvement in decision-making	23(26%)
Care planning	35 (40%)
Crisis planning	7 (8%)

Goal setting	12 (14%)
Strategies for medication	25 (29%)
Medication not whole solution	11 (13%)
5.2.4 Access to services and interventions	13 (15%)
5.3 Focusing upon strengths	14 (16%)

End of published paper

Paper 2 Conceptual Framework qualitative validation paper

Bird, V.J.,* Leamy, M.,* Tew, J., Le Boutillier, C., Williams, J., Slade, M. (2014) Fit for purpose? Validation of a Conceptual Framework for personal recovery with current mental health consumers. The Australian and New Zealand journal of Psychiatry, 48(7), 644-53

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Abstract

Objective: Mental health services in the UK, Australia and other Anglophone countries have moved towards supporting personal recovery as a primary orientation. To provide an empirically-grounded foundation to identify and evaluate recovery-orientated interventions, we previously published a Conceptual Framework of personal recovery based on a systematic review and narrative synthesis of existing models [1]. Our objective was to test the validity and relevance of this framework for people currently using mental health services.

Method: Seven focus groups were conducted with 48 current mental health consumers in three NHS trusts across England, as part of the REFOCUS Study. Consumers were asked about the meaning and their experience of personal recovery. Deductive and inductive thematic analysis applying a constant comparison approach was used to analyse the data. The analysis aimed to explore the validity of the categories within the Conceptual Framework, and to highlight any areas of difference between the Conceptual Framework and the themes generated from new data collected from the focus groups.

Results: Both the inductive and deductive analysis broadly validated the Conceptual Framework, with the super ordinate categories Connectedness, Hope and optimism, Identity, Meaning and Purpose and Empowerment (CHIME) evident in the analysis. Three areas of difference were however apparent in the inductive analysis. These included practical support; a greater emphasis on issues around diagnosis and medication; and scepticism surrounding recovery.

Conclusions: This study suggests that the Conceptual Framework of personal recovery provides a defensible theoretical base for clinical and research purposes which is valid for

use with current consumers. However, the three areas of difference further stress the individual nature of recovery and the need for an understanding of the population and context under investigation.

Keywords

Mental health services, service research, recovery, identity, self-management

Introduction

Personal recovery from mental health problems has been defined as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles…a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness” [2]. This widely accepted definition underpins mental health policy in most Anglophone countries [3] including Australia where the fourth National Mental Health Plan references recovery and social inclusion as top priorities [4]. However, it is still subject to a degree of conceptual confusion and misunderstanding [5-7]. Despite widespread support for the concept, Braslow argues that recovery has become an unquestioned over-arching principle in mental healthcare further stating it to be “a melange of beliefs and values that emerged from a number of disparate intellectual and social movements” [8]. This lack of clarity also extends to consumers [9]. T facilitate the translation of policy into practice, there is a need to operationalise personal recovery so it can be applied and evaluated within clinical and research settings [10, 11].

Conceptual Framework of personal recovery

To provide a theoretical foundation to understand recovery, a systematic review and narrative synthesis of existing recovery models was conducted to develop a Conceptual Framework of personal recovery. Out of this, five key recovery processes were identified which collectively comprise the CHIME framework: Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment. Within each of these categories, a number of sub-themes were included which defined and described the five recovery processes[1].

This Conceptual Framework of personal recovery has already proved to be a useful research utility, providing a taxonomy for categorising different intervention strategies. Further evidence reviews have been conducted into different areas of the CHIME framework, e.g. Hope [12], Strengths [12] and Connectedness, Identity and Empowerment [13]. Individual interventions can also be positioned within the framework, in relation to their intended outcomes. For example studies of peer support [14] or meaningful activities [15] can be categorised alongside interventions addressing Connectedness or Meaning and Purpose respectively. Reviews of recovery measures have also made use of the framework within their analysis [16, 17]. Finally, to test the validity of the Conceptual Framework across different settings, a further review was conducted which established that across different countries the framework captured key aspects of recovery, and could be recommended as the basis for a common international understanding of recovery [18].

Validity and relevance

According to Hammersley qualitative research should be judged according to both validity and relevance [19, 20]. Within this context, relevance relates to whether the study i) addresses meaningful questions to the population of interest, ii) adds to the existing knowledge base, and iii) is generalisable to settings beyond that in which the research was conducted [20, 21]. The Conceptual Framework was based on studies which included many individuals who described themselves as 'in recovery' or 'relatively well and symptom free'. This raises the question as to how valid and useful the Conceptual Framework may be in making sense of the experience of individuals who are currently using mental health services, including those who may or may not define themselves as being 'in recovery'. Therefore, this paper focuses on the first and third aspects of validity and relevance - namely whether the Conceptual Framework is meaningful for current mental health consumers.

Aims

This study aims to explore the validity of the Conceptual Framework using data collected from focus groups conducted with current mental health consumers and to highlight any areas of deviance between the Conceptual Framework and the themes generated from the focus groups.

Methods

Design

This study is part of the REFOCUS programme, a large, mixed methods research programme investigating personal recovery from mental health problems in England [22]. We used three types of triangulation in this study. These were data, methodological and environmental. Triangulation was achieved by comparing data collected from focus groups to a framework developed from the literature. This meant that data collection method (data and methodological triangulation), sampling (data triangulation) and study location (environmental triangulation) all varied. We used triangulation to obtain an in-depth understanding of experiences of personal recovery. Specifically by combining different research methodologies, perspectives and settings we aimed to add rigor, breadth, richness and depth to the analysis [23].

Setting

Seven focus groups with individuals using community-based teams were held at the team bases within three mental health trusts from June to September 2010. The settings were selected to represent a range of metropolitan, urban and semi-rural geographical areas and to be able to draw participants from local populations which differed in terms of socio-economic status, race, culture and ethnicity.

Participants

We recruited a convenience sample of working age adults (aged 18-65 years), who were currently using (or had used in the previous six months) community-based mental health teams. For one focus group, participants were also recruited from voluntary sector organisations within South London. To be included, participants had to be willing and able to discuss their recent experiences of receiving support from mental health community teams. As the sample used within the study was a convenience sample, characteristics of the individuals who declined to take part were not available. Care coordinators were asked to approach a range of people with differing levels of service use and time within services, and efforts were made to contact a range of clinical team types (e.g. early intervention, assertive outreach, forensic, support and recovery) to ensure a diversity of opinions.

We aimed to recruit between six and eight participants per focus group. Prior to the study, we estimated that we would need five to ten focus groups to reach thematic saturation. Data collection was terminated after seven focus groups, because saturation was reached.

Procedure

All participants were recruited through care co-ordinators within community-based mental health teams and via posters displayed within local community-based organisations and hospital outpatient departments. Participants received a £20 as a thank you for their time and participation and were provided with lunch at the conclusion of each focus group session. Participants were given a written information sheet outlining the purpose of the study and were encouraged to ask questions before giving their written informed consent.
Each focus group was moderated by two researchers, one from a professional research background and another who had lived experience of using mental health services. The moderators alternated leading the discussion and acting as support moderator. Each group lasted approximately 1.5 hours.

At the beginning of each group, participants completed a brief socio-demographic questionnaire. Participants were then asked to agree to a number of ground rules, which stressed the importance of every member's opinion, and asked for participants to discuss the question even if they felt their opinion had already been stated. This was further emphasised during the group by the use of prompts which asked if anyone had any other or different opinions to those being expressed. The focus group discussion guide contained open-ended questions that explored participants' perceptions of the term recovery, and also, what services did that either supported or hampered their recovery. For instance, "What does recovery mean to you?", "How has your community mental health worker/team helped or supported you in your recovery?", "What about the ways that your

community mental health worker/team does not help or support you in your recovery?" and "What could your community mental health worker/team be doing differently to better support your recovery?"

Analysis

The seven focus groups were audio-taped and transcribed verbatim. Transcripts were anonymised and imported into N-Vivo, (version 7, QSR international) for analysis. In order to explore the validity of the CHIME framework of personal recovery, two separate approaches to analysis were concurrently employed. Firstly, the focus groups were analysed thematically using deductive coding. The deductive coding framework comprised the five superordinate categories of the previously published Conceptual Framework [1] and are detailed in Table 1 (with the full deductive coding framework available in the Online Data Supplement). Secondly, in order to identify potential areas of difference, inductive coding was used. Inductive coding ensured the coders were alert to themes and patterns within the data which would otherwise been obscured, reframed or left undetected had the data only been analysed using the deductive codes. Particular attention was paid to any deviant cases and new themes emerging from the focus groups that were not adequately captured in the deductive framework.

Table 1: Deductive coding Framework (Taken from [1])

Super ordinate categories	Subordinate category
Connectedness	Peer Support and support groups Relationships Support from others
Hope and Optimism	Hope inspiring relationships Motivation to change Belief in the possibility of recovery Positive thinking Having dreams and aspirations
Identity	Dimensions of identity Rebuilding / redefining a positive sense of identity Overcoming stigma
Meaning and purpose	Meaning of mental illness experience Spirituality (including development of spirituality) Quality of life Meaningful life and social goals Meaningful life and social roles Rebuilding of life
Empowerment	Personal responsibility Control over life Focusing on strengths

Two independent coders (VB and ML) conducted both the inductive and deductive coding. The coders met to review their coded passages and to agree on the major themes and to discuss coding differences to arrive at a consensus. This process of investigator corroboration is designed to maximise the validity, trustworthiness and safeguards against bias within the analysis process. As part of an ongoing process of researcher reflexivity, coders kept theoretical memos to capture thought processes and ideas as they developed. This ensured that any pre-conceived ideas about the data were recorded and that the impact of previous knowledge, including professional background, on the analysis was openly discussed.

Ethical approval

Ethical approval for the study was granted by the South East London Research Ethics Committee 4 England.

Findings

Sample characteristics

Forty-eight individuals participated in the seven focus groups. The focus groups were conducted in three NHS trusts in England: 2gether Gloucester Foundation trust (n=2); Leicester Partnership Trust (n=2) and South London and Maudsley Foundation Trust (n=3). The demographic characteristics of the participants are detailed in Table 2.

Table 2 – Sample characteristics of participants (n=48) included in the focus groups

Characteristics	Participants
Gender (N, %):	
Female	20 (58%)
Male	28 (42%)
Age (Mean, SD)	42.1 (10.4)
Ethnicity (n, %):	
White British	16 (33%)
White Irish	1 (2%)
White Other	1 (2%)
Black/ Black British - African	11 (23%)
Black/ Black British - Caribbean	9 (19%)
Black Other	1 (2%)
Asian / Asian British – Indian	2 (4%)
Asian / Asian British - Pakistani	1 (2%)
Asian other	1 (2%)
Mixed race	2 (4%)
Other	4 (8%)
Diagnosis (n, %):	
Schizophrenia or Schizoaffective disorder	19 (40%)
Bipolar Disorder	8 (16.5%)
Depression	6 (12.5%)

Anxiety	1 (2%)
Other	2 (4%)
Did not want to disclose	12 (25%)
Mental health team type (n, %):	
CMHT	6 (13%)
Support and recovery	15 (31%)
Early intervention service	5 (10%)
Assertive outreach	9 (20%)
Forensic	1 (2%)
Rehabilitation	1 (2%)
Continuing care	5 (10%)
Other	4 (8%)
Did not want to disclose	2 (4%)
Time in MH services years (mean, SD)	11.6 (7.0)
NHS trust (n, %):	
SLAM	27 (56%)
Gloucester	10 (21%)
Leicester	11 (23%)

The five recovery super ordinate themes Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment, comprising the CHIME framework are firstly presented. . Where data arising from the inductive coding process was seen to fit within the parameters of the CHIME framework for example, the inductive coding suggested a change in emphasis of one of the categories within CHIME it is reported alongside the other data relating to that CHIME theme. This is followed by three new themes which emerged from the inductive analysis. These new themes were i) practical support; ii) issues around diagnosis and medication, and iii) scepticism surrounding recovery Reported themes within this paper arose consistently across focus groups, unless otherwise stated.

Connectedness

Connectedness emerged as a very important process in recovery and included a number of subthemes such as peer support, relationships and support from others. Central to this super ordinate theme was the sense of being connected to others. All three subordinate themes were evident in the deductive analysis.

Peer support and support groups

There were many different people who could offer support to individuals, including close family friends, members of the community and mental health professionals. Participants frequently emphasised the importance of peer support, received by attending organised groups, from contact with peer support workers, or informally, from friendships that developed among people with lived experience.

"Like I said before you know they're organising a group, hearing voices groups and um, it's very helpful. We meet... every Thursday and we share our experiences with each other and it has helped a lot." (Leicester FG2, Female participant)

Support from others

For many people, having a range of personal relationships with others was critical to the recovery of a life worth living. For some, connectedness went beyond immediate family and friends to include feeling connected within the wider community, or feeling part of society.

"You're not recovered if you no longer cut your wrists or take an overdose...that's not a life. For most people you're recovered if you have friends, if you have family or if you have a job." (SLaM FG1, Female participant).

Relationships

Finally, supportive and collaborative relationships with professionals were seen as having a positive impact on recovery.

"Whereas I've got this nurse who sits down and listens to what I have to say…., gives me her opinion of things and provides with the right medications for me. That has helped me recover quicker". (Gloucester FG2, Female participant)

Hope and Optimism

Hope was central to most individuals, especially in the early stages of recovery where people described experiencing a reawakening of hope after despair. Hope was defined by a number of secondary categories, namely "having the motivation to change", "having dreams and aspirations", "a belief in the possibility of recovery" and "positive thinking". All of these categories emphasise the idea that recovery is an active process, rather than something that is "done to" the person.

"Yeah, but hope is one of those things that you have to do yourself. No one's going to hope for you, really. And optimism, because there is a lot of optimism" (Gloucester FG1, male participant).

Hope inspiring relationships

Central to many of the factors defining hope was the presence of hope-inspiring relationships. This subordinate category was frequently apparent in the deductive analysis, where relationships which promoted hope were discussed. These relationships could be with family, friends, and professionals or with a higher power and all shared the common characteristic that they engendered a belief that recovery was possible. For some participants, role models provided his hope for the future.

"The employment specialist, she was an ex-patient and I find that a real positive. It makes me realise there's hope, because I never thought there was hope. I thought I just can't get a job, but there is hope, y'know." (SLaM FG3, Male participant)

Equally powerful was the evidence that emerged from the inductive coding of how professionals could reduce hope and the belief in recovery.

"Well for me when I got struck down with the mental illness. I went to the usual psychiatrist and they told me 'Ah. This is a chronic illness. That means you will have to live with it'. So the Recovery for me is a dirty word. Right?" (SLaM FG3, Male participant).

Identity

Rebuilding / redefining a positive sense of identity

Mental health problems can dislocate or undermine people's sense of identity and self-worth. For many people, the key to recovery can involve redefining, or regaining a positive sense of self. For some, the process of recovery is seen as involving some transformation of identity (discovering a new 'me').

"So when you let go of the old person and say 'There's going to be a new one, a better one' then you'll go quicker towards recovery. That's what I discovered." (SLaM FG2, Male participant)

However, not all participants shared this perspective and, from the inductive coding, it emerged that some participants were holding on to the aspiration of reclaiming their prior social identity and sense of self:

"Recovery for me is, two years ago I have family, job, every single thing. And I want to recover my previous life." (SLaM FG2, Male participant)

Multiple dimensions of identity

Regardless of whether the individual wanted to return to their pre-illness life or redefine a new sense of self, for most individuals it was important that they saw themselves as more than just their diagnosis. This was linked to the idea that an individual's identity could not be viewed in a unitary way. Instead multiple dimensions of identity were important and included cultural, ethnic and sexual identity. In particular, having mental health services and professionals who valued different dimensions of identity and treated you as an individual, was crucial.

"She hasn't looked at me at the colour of my skin or my culture or background, she's just taking me as an individual" (Gloucester FG2, Female participant)

Overcoming stigma

The final theme captured in the category identity was “overcoming stigma”. Part of the journey to regain a positive sense of self was to overcome stigma and hence it was seen that wider society needed to be onboard with recovery.

> *“When I heard that I had a mental health problem I ran a mile. I was not connecting with the system, so, recovery, it’s not just on us, it’s on the outside as well. Because once they recover and there’s no longer that stigma against mental health and then we might feel a bit better in ourselves”.* (SLaM FG3, Female participant)

Meaning and Purpose

Meaning and purpose was a broad category and included many inter-related elements. These themes ranged from finding meaning in the illness experience to rebuilding life and having meaningful social roles. This category also included spirituality and developing spirituality (not shown). In essence, living a meaningful and purposeful life whatever that meant to the person was the goal of most individuals.

> *"For me simply the definition of recovery is having the life you want. So it's not every day you can see your friends. It's not every day you can...but that on the days that you can do the things that you would do if you didn't have a mental illness, those are recovery days, in a nutshell.” (*SLaM FG1, Female participant)

Meaningful life and social roles

Individuals stressed that the activities and occupations that made life meaningful for people without mental health problems, or "normal" people as they termed it, were the same activities and occupations that made life meaningful if you had a mental health problem:

> *"I think psychiatrists can do worse than just to think.....what's important in their daily life, service users are no different. All the things that everybody, every normal person wants, service users want exactly the same, they just need support to get it.” (*SLaM FG1, Male participant)

Rebuilding of life

Having a meaningful life was also about having a purpose or a reason to get up each day. For some individuals this included volunteering, which allowed them to feel that they were giving back to the community and achieving within their day to day lives. This for many was part of rebuilding a meaningful life

> *"I volunteer at the [service for disabled people] and I feel like I'm contributing to people. So when a week's gone by I don't think, 'Oh, that's another wasted week.' I think I've done something useful."* (Leicester FG1, Male participant)

Meaning of the mental illness experience

Finally, recovery for some individuals included understanding or finding meaning in their mental illness experience which ranged from spiritual or religious meanings through to adoption of a medical view of mental illness. Giving an experience meaning was seen as normalising that experience, which in itself could have positive implications including increased acceptance and reduced self-stigma.

Empowerment

Empowerment emerged as a central recovery process which was achieved in different ways, including, personal responsibility, having control over life and focusing on strengths.

Personal responsibility

For others, empowerment specifically meant being involved in decision making and having some say in their care and treatment, particularly where medication and hospitalisation were concerned. Personal responsibility could also involve positive risk taking, particularly in the context of care planning and goal setting – and it was helpful when this was supported by the professionals involved:

> *"I always used to tell the doctor if I was reducing. I would inform him or her, 'I'm going to reduce my medication You don't mind, do you?' and he'd say, 'Well, we're all against it but it's up to you.' But because if I had a problem I'd go back to him, 'I've got a problem and I've increased it again.' So they got used to that and they started to trust me*". (Gloucester FG1, Male participant)

Interestingly, from the inductive coding we found that not all participants wanted to have control over their medication and saw it as the professionals' role to deal with this:

> *"I would avoid self medication. Some people are allowed to choose, to a certain degree, what dosage they take, what times they take. I would always want a professional person to say, 'That is what you require for your illness.' Mess with tablets, it could end up a catastrophe, couldn't it?" (Gloucester FG1, Male participant)*

This suggests a more nuanced understanding of empowerment which involves taking informed choices as to which sorts of decisions people make for themselves and which they may wish to leave with professionals.

Control over life

For some, feeling in control meant being able get on with day-to-day life, even when symptoms were present. This included maintaining good physical and mental health,

using self-management strategies, accessing self-help materials or seeking professional support as appropriate.

> *"I know my symptoms and I think other people around me do know when I'm not well. But, like I said, you have to protect yourself as well. You have to make sure that you keep yourself well and happy." (*Leicester FG1, Male participant)

Focusing on strengths

The final area covered in empowerment was focusing on strengths, where individuals often talked about adopting roles which were built around their personal strengths and resources:

> *"My staff are very encouraged about the good stuff I'm doing. It might not be a big deal to other people here, but little things, just like getting up in the morning and not staying in bed, having a tidy flat, clean and tidy flat they're very encouraging. And my staff are focusing on good points because that helps instead of just the bad stuff."* (Gloucester FG2, Female participant).

Emergent themes arising from the inductive coding:

Three new categories were apparent in the inductive analysis, which could not be subsumed within the existing themes included in the CHIME framework. Consequently, the following three themes represent additions to the categories included in the original framework.

Practical support

Some participants stressed the importance of practical support to improve their material circumstances, access wider life opportunities or simply to survive on a day-to-day basis at times when they were less able to manage daily activities and tasks. This, in turn, enabled them to move forward with their recovery. During the focus groups individuals explicitly talked about the type of support they wanted from services and mental health professionals. Whereas much of the recovery literature has tended to focus more on the relationship qualities, participants were equally interested in practical outcomes that made their lives more liveable:

> *"My current social worker's done really nice things for me. I mean she's introduced me to a place that decorates a room of yours, maybe one room a year, and that's really improved my spirit."* (SLaM FG1, Male participant)

Although improvements in material circumstances may be seen to have a knock-on effect on other key processes such as giving hope or empowerment, it is not easy just to subsume this within one of the already identified recovery processes.

Issues around diagnosis and medication

Another theme that emerged from the inductive coding was a greater emphasis on medication and diagnosis. As discussed above, some of this may be seen to relate to the theme of empowerment – participants either taking control over their medication or wishing to leave this responsibility with clinicians. However, some participants went beyond this - for example highlighting issues around diagnosis, and seeing misdiagnosis as potentially impeding recovery**:**

> *"I think also… if you're not diagnosed properly you're never going to recover."* (Gloucester FG1, Male participant)

Scepticism surrounding recovery

Finally, one theme which may reflect current economic trends which for many consumers has resulted in a loss of services and cuts to mental health provision was that recovery was greeted with a certain level of scepticism by focus group participants.

> *"I think recovery might be some sort of...I don't know, maybe this is a bit paranoia coming out, but it might be some way of the system coping with under resource. So they'd rather shift people who aren't completely recovered, into the community"* (Gloucester FG1, Male participant)

Discussion

Our main finding is that the themes generated from the focus groups provided evidence to support the validity of the recovery processes identified in the Conceptual Framework of recovery. Broadly, the five super ordinate categories of the framework, namely Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment were all supported within the analysis. Furthermore, the second order categories included within CHIME e.g. Relationships, Support from others, Hope inspiring etc. were also apparent, although the inductive analysis did indicate some modifications to the definitions of each category. This broad validation indicates that the CHIME framework is a valid and relevant representation of recovery processes for current mental health consumers and is therefore a useful theory-based tool within research and clinical practice. The focus on the inductive analysis highlighted additional aspects that were not captured or emphasised in the original framework. In particular, the analysis suggested three new categories should be included as second or third order categories within the framework. These were i) practical support; ii) issues around diagnosis and medication, and iii) scepticism surrounding recovery. The additional themes highlight the importance of qualitative work and involving the particular stakeholder group or community within the research to ensure that any underpinning theory is a good fit and appropriate to the particular context.

One emergent category of particular importance to service provision was the significance of practical support in relation to material circumstances, accessing opportunities and

managing day-to-day survival. The inductive analysis suggests that practical support should be a second order category within Connectedness (instead of being a lower third order category). This finding regarding the importance of practical support contrasts with the recent literature evaluating the contribution of support workers to recovery processes, which often emphasise the importance of worker-consumer-relationships [24] and the teaching of self-management skills rather than simply providing practical support [25]. The findings of the focus groups do however echo those of the 2010 Survey of High Impact Psychosis (SHIP) which is the second Australian National Survey of Psychotic Illness. The survey highlighted that individuals with psychosis listed finances, housing and employment as their most pressing concerns alongside social isolation and that these areas were more of a concern to individuals than psychotic symptoms or ill health. Furthermore, 30% of individuals in the survey reported the need for practical assistance, including help with finances and seeking employment [26-29].

Other differences emerged, at least in emphasis, between the data from the focus groups and the recovery literature analysed for the narrative synthesis. Within the literature it is often assumed that recovery involves becoming a new person and discovering new social roles [30-32], with a loss of the old self [33]. Indeed, the most widely cited recovery definition talks about the development of new meaning and purpose [2], whereas Whitwell talks about the “myth of recovery" and returning back to the same as before [34]. In contrast to the literature, participants in the present study expressed more mixed views, with some seeing recovery as returning to a pre-illness life. Although this does not suggest a change to the CHIME framework, this difference in emphasis has now been incorporated into the definition of Identity.

Linked to this shift in emphasis, there was also more concern with issues around medication and diagnosis, with correspondingly less emphasis on people’s own agency in confronting challenges and taking control over all aspect of their recovery journeys. One possible reason for these differences may relate to stages within the recovery journey. Within the present study, participants were recruited across community mental health teams and were likely to include people at earlier stages of their recovery journey. In contrast, the Conceptual Framework review tended to reflect the experiences of individuals further on in their recovery. This difference between the samples could explain how some of the focus group participants were more in touch with the identities and lifestyles that they had lost, whereas those whose experience informed the Conceptual Framework were more in touch with the new identities and lifestyles. The increased emphasis on diagnosis and medication suggests modification of the empowerment definition, and the inclusion of

a new second or third order category covering the issue of diagnosis and medication, within the super ordinate theme of empowerment.

Strengths and limitations of the approach

One of the strengths of this paper was in the use of triangulation. Specifically, we used three types of triangulation (data, methodological and environmental) by comparing data collected within focus groups to a framework developed from the literature. Triangulation uses the relative strengths of different data sources and approaches to detect inconsistencies and thereby uncover deeper meanings within the data [20, 35] . Secondly, this is the first study to specifically test the validity and relevance of an existing framework of personal recovery developed through a systematic review. This coupled with an earlier paper [18] which assessed cross-cultural validity suggests that the Conceptual Framework of recovery is a useable and valid tool for use in future research and practice.

Despite the relative strengths of the study, there are four main limitations. First, the emergent categories included in the Conceptual Framework were only one way of grouping the findings, so the five recovery processes Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment which make up the CHIME framework could be amended if the narrative synthesis and validation process were repeated [36]. Secondly, the framework should not be seen as definitive. As recovery is an individual and dynamic process, the Conceptual Framework is not intended to be a rigid definition of what recovery 'is', but rather a resource to inform future research and clinical practice. The individual nature of recovery was highlighted in the present study by the three new themes arising from the inductive analysis. Thirdly, although as noted triangulation can be seen as a strength of the study , others have argued that using member checking and triangulation as a form of validation is not without problems [35]. Specifically, we would expect different understanding of the same phenomenon, especially as the accounts of participants in the focus groups may be formed for different reasons compared to the accounts formed by researchers. However within this study, we have used multiple types of triangulation in addition to participant triangulation as detailed above. Finally, one limitation concerns the analysis, in which the same reviewers conducted the inductive and deductive analysis concurrently. The deductive framework may have influenced the inductive analysis, such that differences were incorporated into the existing categories of the framework, instead of being seen as new categories in their own right. To minimise this bias, the reviews independently coded the transcripts and kept reflective notes about the process.

Clinical implications

One of the problems identified with recovery in clinical practice is the lack of clarity regarding definition [7, 37, 38], with Braslow arguing that recovery have become "melange

of beliefs and values"[8]. The Conceptual Framework validated in this study offers one solution to this problem as it provides a useable and valid definition of recovery for use within research and practice.

Confusion surrounding the meaning of recovery has also raised concerns that recovery has been co-opted by the system [31, 39]. This increased scepticism around recovery is common to both staff and consumers, where concerns such as recovery being the "next new thing"[30], tokenism instead of genuine partnership and user involvement [40] and a drive towards autonomy resulting in a withdrawal of support [32] have been expressed. Consistent with these concerns, scepticism surrounding recovery was expressed by focus group participants and suggests the need to modify the framework to include this as a new second or third order category. People not only had concerns about the terminology used, but many participants also saw recovery as the way the system could cope with the increased demands whilst in an economic climate of cut-backs and financial savings. This view is echoed within the literature, where the concern that recovery will be misused as a post-hoc justification for reducing and cutting services has been voiced [39, 41]. This increased scepticism of recovery, also raises the question of whether such concerns are a by-product of individuals coming into contact with mental health services that are not currently recovery focused such that staff and system-level concerns about recovery are communicated to consumers.

Research implications

The use of systematic reviews to design interventions and as tools for decision-making has increased exponentially in the last decade, leading to concerns that what is reported in the literature might not always be applicable and transferrable to the population and context under investigation. [7, 11]. Although this study supports the use of concepts developed on the basis of systematic reviews, the identified differences in emphasis highlight the importance of conducting qualitative work with the population of interest to ensure that the concepts are valid and of relevance.

Another research implication is that in addition to the lack of conceptual clarity, a the recovery literature has been criticised for the lack of evidence base [30]. Proponents of evidence base medicine argue for concepts that are "objectively measureable" [42]. Recovery and evidence-based medicine can be seen as creating a tension between the need to develop objective empirical evidence comprising meta-analytic aggregation of randomised controlled trials and the individualised and unique nature of personal recovery. The Conceptual Framework offers a solution to this tension by providing a useable basis for further empirical work and research to build upon. It provides a framework to guide the development of an evidence base by identifying target areas for intervention and highlights

potential outcomes that trials could focus upon and measure. Currently, the conceptual of recovery is being used as the theoretical foundation for two large scale studies - the REFOCUS cluster RCT within two mental health trusts in England [22] and within the Principles Unite Local Services Assisting Recovery (PULSAR) recovery project which has received funding from the Victoria Government to test a practical approach to providing recovery-orientated mental health services [43].

Conclusion

This study demonstrated that an existing Conceptual Framework of personal recovery is both valid and relevant for use within clinical practice and research. Despite differences in the participants, particularly in the stages of recovery, the five main recovery processes of the Conceptual Framework remain relevant to mental health consumers. However, the areas of difference highlighted and the subsequent modifications to the framework, may suggest that conceptualisations of recovery in the literature are primarily based on the experiences of consumers who are further along their recovery journeys than those currently using services. Consequently, some aspects of the earlier stages of recovery, including the need for practical support have been under-represented in the recovery literature at present. Furthermore, this study highlights the importance of conducting initial qualitative work to ensure the relevance of any existing concepts to the context and individuals under investigation.

Conflict of interest

All authors declare they have no conflicts of interest

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End of published paper

Appendix 3: Conceptual Framework review eligibility table

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
AHERN2001	Electronic	Literature review	Include	
AJAYI2009	Hand search (web)	Qualitative interviews with 48 people with lived experience of mental health problems	Include	
ANDERSON2000	Citation	Monograph	Include	
ANDRESEN2003	Electronic	Literature review	Include	
ANTHONY1993	Electronic	Theoretical paper outlining the assumptions of recovery orientated practice.	Include	
ARMOUR2009	Electronic	Semi-structured interviews with African American consumers.	Include	
ARMSTRONG2009	Electronic	Literature review and focus groups using concept mapping	Include	
ASMUNDSSDOTTIR2009	Electronic	Qualitative methods used with a cross-section of participants who considered themselves as psychiatric “survivors”	Include	
BARTON1998	Electronic	Review and opinion article	Include	
BAXTER1999	Electronic	Overview of a recovery orientated service	Include	
BONNEY2008	Electronic	Literature review and thematic analysis	Include	
BORG2008	Electronic	Qualitative study using narrative phenomenological methods based on interviews with individuals in recovery.	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
BRADSHAW2007	Electronic	60 participants with a severe mental illness took part in a 3 year phenomenological study.	Include	
BRADSTREET2004	Hand search web	Paper notes that a number of sources have been used in the development of the discussion paper, including a literature review and consultation with service users.	Include	
BROWN2007	Electronic	Qualitative analysis of the narratives of 64 individuals with lived experience of mental illness.	Include	
CAMPBELL2008	Electronic	Book chapter based on a literature review	Include	
CLEARY2009	Electronic	Literature review	Include	
DAVIDSON2005	Electronic	Literature review	Include	
DAVIDSON2008B	Citation	Review of first-person accounts in the literature. Consultation of these results occurred with stakeholders from both the mental health and addiction fields	Include	
DAVIDSON2009	Hand search (web)	Literature review	Include	
DAVIS2007	Electronic	Book chapter including a review of the literature	Include	
DIAMOND2006	Electronic	Literature review focuses on schizophrenia	Include	
DMHAS2008	Hand	Details not provided, large funded	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
	search (web)	project		
ELLIS2003	Electronic	Literature review used to development measure of recovery. The measure is further tested in the paper.	Include	
FALLOT1998	Electronic	Individual narratives	Include	
FANON2008	Hand search (web)	Individual interviews and questionnaires with African and African Caribbean males using a local voluntary sector mental health service.	Include	
FISHER1994	Electronic	Overview of model based on the experiences of people with mental health problems	Include	
FORCHUK2003	Citation	Semi-structured interview with ethnographic method, including opinions of consumers, staff and family	Include	
GAGNE2007	Electronic	Literature review and discussion paper	Include	
GLOVER2005	Electronic	Editorial / opinion piece	Include	
HOPPER2007	Electronic	Literature review	Include	
IMHC2008	Hand search (web)	Literature review and consultation process	Include	
JACOBSON2000	Electronic	Overview of the literature	Include	
JACOBSON2001	Hand	Based on the work of the Wisconsin	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
	search (web)	recovery implementation task force.		
JACOBSON2001A	Electronic	Dimensional analysis of personal narratives	Include	
JENKINS2006	Electronic	Ethnographic study looking at the subjective experience of recovery from schizophrenia	Include	
JENSEN2007	Electronic	Semi-structured interviews with individuals considered to be in recovery from SMI	Include	
KELLY2005	Electronic	Literature review and individual narratives.	Include	
KING2007	Electronic	Book chapter including a review of the literature and personal lived experience.	Include	
LAPSLEY2002	Hand search (web)	Qualitative analysis of 40 narratives. Focuses on bicultural research with Maori and non-Maori people	Include	
LIBERMAN2002	Electronic	Literature review and focus groups	Include	
LIBERMAN2002B	Electronic	Introduction to special issues	Include	
LIBERMAN2005	Electronic	Literature review and validation study using the definition as a framework and looking at the response of key stakeholder groups.	Include	
LUNT2002	Electronic	Theoretical paper	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
MANCINI2005	Electronic	Qualitative analysis of 15 personal accounts regarding recovery from severe psychiatric disability.	Include	
MANCINI2006	Electronic	Semi-structured interviews with people with psychiatric disabilities	Include	
MANCINI2007	Electronic	Interviews with psychiatric survivors using grounded theory for the analysis	Include	
MANCINI2008	Electronic	Literature review applying an empirically validated framework	Include	
MARKOWITZ2005	Electronic	Reviews literature	Include	
MEAD2000	Citation	Personal narratives of two psychiatric survivors	Include	
MERRYMAN2007	Electronic	Literature review and interviews with a convenience sample of 20 people with serious and persistent mental illness	Include	
MEZZINA2006	Electronic	Visual model based on literature review and research. Very socially focused.	Include	
MHPF2008	Hand search (web)	Forums with service users, carers and providers and work conducted within pilot sites	Include	
MHPF2009	Hand search (web)	Pilot study examining the effectiveness of the recovery star for people from BAME backgrounds. Conducted focus groups and surveys with service users.	Include	
MHRECOVERYWORKGROUP2009	Web-based search	Qualitative study – focus groups	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
MORSE2000	Electronic	Book chapter reviewing literature on mental health, homelessness and recovery.	Include	
NHSScotland2008	Electronic	Project report describing the findings of three projects assessing recovery in BME communities. Uses focus and discussion groups to gather data.	Include	
NICHOLLS2007	Hand search (web)	Literature review covering the key findings from the research	Include	
NIMHE2004	Electronic	Literature review and consultation process.	Include	
NOISEUX2008	Electronic	Semi-structured interviews with 41 participants, using grounded theory to analyse the data. Includes multiple perspectives (person with lived experience, carer and mental health professional perspectives.).	Include	
NOORDSY 2002	Hand search (web)	Focus groups with consumers and consumer-professional interactions.	Include	
OADES2005	Electronic	Literature review	Include	
OCHOCKA2005	Electronic	Longitudinal qualitative study involving 28 in-depth interviews with people who have experienced serious mental illness.	Include	
ONKEN2007	Electronic	Literature review and dimensional analysis	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
PEDEN1993	Electronic	Qualitative research design using Peplau's interpersonal theory. 7 women who had been hospitalised at some point with depression.	Include	
PIAT2009	Electronic	Qualitative interviews with 60 consumers of mental health services	Include	
PIAT2009A	Electronic	Qualitative study with consumers of mental health services	Include	
PITT2007	Electronic	Semi-structured interviews with people with psychosis. IPA used for the analysis.	Include	
PLUM1987	Electronic	Qualitative study of 20 autobiographical accounts of people with lived experience of serious mental illness	Include	
PROVENCHER2002	Electronic	Semi-structured interviews looking at themes and dimensions of recovery	Include	
RALPH1999	Hand search (web)	Narrative of the Recovery Advisory Group	Include	
RALPH2000	Electronic	Literature review(focuses on a sample of published and unpublished literature)	Include	
RAMON2007	Electronic	Literature review	Include	
REPPER2003	Electronic	Book chapter reviews personal accounts and narratives published in the literature and presented at conferences.	Include	
RESNICK2005	Electronic	Factor analysis of questionnaire data about the factors of recovery.	Include	
RIDGE2006	Electronic	Qualitative interviews with people with	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
		lived experience of depression.		
RIDGWAY2001	Electronic	Qualitative analysis of first person accounts	Include	
SAMSHA2004	Hand search (web)	National consensus statement involving 110 expert panellists including service users, carers and professionals.	Include	
SCHON2009	Electronic	Grounded theory used to analysis the semi-structured interviews included in three previous studies.	Include	
SCHRANK2007	Electronic	Narrative review	Include	
SCIE2008	Electronic	Literature review and policy document	Include	
SLADE2009	Hand-searched	Theoretically based, empirically informed model, based on a review of the recovery literature.	Include	
SMITH2000	Electronic	Interviews with people with serious mental illness	Include	
SONG2009	Hand search	In-depth qualitative interviews with 15 consumers in recovery.	Include	
SOWERS2005	Electronic	Literature review	Include	
SPANIOL2002	Electronic	Qualitative analysis of longitudinal semi-structured interviews of consumers with schizophrenia.	Include	
SPANIOL2003	Electronic	Book chapter based on literature review	Include	
STEEN1996	Electronic	Phenomenological analysis of semi-structured interviews	Include	
SULLIVAN1994	Citation (book reference)	Semi-structured interviews with 46 former and current mental health consumers	Include	

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
SUNG2006	Electronic	In-depth case analysis of 8 students with current lived experience of schizophrenia	Include	
SYDNEYWEST2008	Hand search (web)	Wellness promotion plan developed through the experiences of teaching the mental health outcomes and assessment tools and from the experience of mental health consumers	Include	
TOOTH2003	Electronic	Interviews and focus groups with thematic analysis used to analyse the data. Themes are then compared to the literature.	Include	
TORREY2000	Electronic	Qualitative analysis of first-person accounts	Include	
WARREN2003	Electronic	Literature review, thematic analysis of text and individual interviews	Include	
WARREN2003	Electronic	Literature review, qualitative analysis of writing and individual interviews	Include	
WHITEHORN2002	Electronic	Cross-sectional study design	Include	
YOUNG1999	Electronic	Semi-structured interviews using grounded theory for the analysis.	Include	
2006	Electronic	Literature review	Exclude	Looks at an existing model of recovery and relates this to the way hospitals should operate. Also has quality standards.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
ADAME2008	Electronic	Narratives of psychiatric survivors	Exclude	Presents the individual narratives without any synthesis.
ADAMS1998	Electronic	Literature review	Exclude	Does not present a model of recovery.
ADAMS2009	Electronic	Study using a framework to rate mental health transition	Exclude	Focuses on mental health policy and implementation.
ADDINGTON2005	Electronic	Literature review and effectiveness study looking at family work in early psychosis.	Exclude	Presents a model of recovery for the whole family including the individual with psychosis.
ALLEN1997	Electronic	Quantitative and qualitative data combining postal surveys and individual interviews.	Exclude	Evaluates a service model of recovery and its implementation.
ALLOTT2002	Electronic	Literature review	Exclude	Describes existing models of recovery – use for reference check.
ALLOTT2002A	Electronic	Literature review	Exclude	Does not present an original model of recovery. Use for ref check
ALLOTT2005	Electronic	Overview of literature	Exclude	Doesn't present a model, gives existing definitions.
AMERING2009	Electronic	Whole book – provides good overview of existing concepts	Exclude	Discusses existing models – use for reference check.
ANDRESEN2006	Electronic	Literature review and postal survey	Exclude	Describes an existing model – check refs.
ANON2007	Electronic	SCIE literature review	Exclude	Publishes a common purpose
ANON2007	Electronic	Commentary	Exclude	Does not present a model of recovery.
ANTHONY1991	Electronic	Literature review	Exclude	Does not present a model of recovery.
ANTHONY2003	Electronic	Editorial	Exclude	Does not present a new model of recovery

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
ARONS1994	Electronic	Opinion paper.	Exclude	Does not present a model of recovery. Lists service values – not recovery specific.
ASHCRAFT2006	Electronic	Opinion article	Exclude	Does not present a model of recovery – discussion paper.
ASLAN2008	Electronic	Opinion article	Exclude	Details THRIVE manual and doesn't present a model of recovery.
AYASH2008	Electronic	Reflections and developments of a service	Exclude	Does not present a model
BARKER2001	Electronic	Background / opinion article	Exclude	Presents an overview of the implementation and evaluation and not the model.
BARKER2001A	Citation	Overview of the development of the tidal model	Exclude	Does not present a model of recovery.
BARKER2001B	Citation	Review / opinion article	Exclude	Does not include a model of recovery
BARKER2003	Electronic	Opinion article	Exclude	Describes the implementation and features of an existing recovery model.
BARKER2005	Electronic	Book outlining the tidal model	Exclude	Does not present a usable/ concise model of recovery. Focuses on a model of nursing practice.
BARKER2008	Electronic	Opinion article	Exclude	Evaluates an existing model (tidal model)
BASSET2008	Electronic	Literature review	Exclude	Reviews service user involvement only.
BEEBLE2009	Electronic	Nation survey of people with lived experience of mental illness	Exclude	Looks at the relationship between power and an existing model of recovery – check refs.
BELLACK2006	Electronic	Literature review	Exclude	Presents existing models of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
BELLACK2007	Electronic	Obituary	Exclude	Not relevant
BERGER2006	Electronic	Quality improvement study – evaluation of the Tidal model	Exclude	Evaluates an existing model – the Tidal model.
BLACKMAN1981	Electronic	Factor analytic study of 146 people with lived experience of mental illness	Exclude	Factor analysis of clinical recovery in a forensic setting.
BLEDSOE2008	Electronic	Comparison of two evidence-based interventions with factors that promote and hinder recovery	Exclude	Presents only an existing model – use for meaningfulness review.
BMERG	Hand search (web)	Report from the women's BME project	Exclude	Doesn't present a model of recovery, instead reports on the project. Include for PhD
BOND2008	Electronic	Narrative review of the area	Exclude	Does not present a model or framework of recovery.
BORKMAN1998	Electronic	Literature review	Exclude	Not relevant
BRADSHAW2006	Electronic	Personal experience of people with psychosis	Exclude	Does not present a useable model of recovery, instead focuses on the experience of people with psychosis during the initial stages of a treatment programme.
BROOKES2006	Electronic	Overview of the literature	Exclude	Present an overview of the tidal model.
BROWN2002	Electronic	Introduction to special issue on recovery	Exclude	Presents an overview of the special issue
BROWN2008	Electronic	Correlational study	Exclude	Only looks at predictors of recovery using an existing model – check for refs.
BUCHANAN-BARKER2006	Electronic	Opinion article	Exclude	Presents and describes an existing model.
BUCHANAN-BARKER2008	Electronic	Literature review	Exclude	Service-based model

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
BUCKLEY2007	Electronic	Focus groups with consumers using peer support services	Exclude	Doesn't present a model of recovery.
BUSSEY2008	Electronic	Literature review	Exclude	Population not relevant- substance misuse.
CAMH2009	Hand search (web)	Literature review and recommendations framework	Exclude	Focus is on people with learning disabilities and co-existing mental health problems. Also presents existing definitions.
CAMPBELL2007	Electronic	Literature review and documentary analysis	Exclude	Reviews the literature on recovery training and not recovery. Useful for systematic reviews.
CARPENTER2002	Electronic	Literature review	Exclude	Overview of existing models.
CASTILLO2005	Electronic	Literature review	Exclude	Present an overview of existing models and definitions of recovery.
CHADWICK1997	Electronic	Report on patient experience of psychosis	Exclude	Does not present a useable model of recovery, instead focuses on the experience of people with psychosis.
CHOPRA2009	Electronic	Literature review	Exclude	Describes existing models of recovery and gives an overview of the strengths based model.
CLARKE2006	Electronic	Theory and research behind Collaborative goal technology	Exclude	Does not present a model of recovery. Focuses on CGT
CLEARY2009A	Electronic	Questionnaire with staff assessing the concept of recovery from different professional perspectives.	Exclude	Does not present a model of recovery but uses an existing model.
CLEMENT1997	Electronic	Literature review	Exclude	Presents existing models of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
CLOSSEY2008	Electronic	Opinion article outlining the values of a service	Exclude	Does not include a new model of recovery but defines an earlier model. Does include some service values – should this be classed as a model?
COHEN2009	Electronic	Cohort study	Exclude	Study is based on an existing model of recovery.
COLEMAN2004	Electronic	Narrative / personal account	Exclude	Does not present a concise or original model of recovery, Pg. 45 does present a model by Carling – no details of paper (unavailable)
COOK1997	Electronic	Literature review	Exclude	Focuses on family research and does not present a model of recovery.
COPELAND2001	Electronic	Opinion article	Exclude	Paper details and describes the WRAP.
CORRIGAN1999	Electronic	Investigation into the psychometric properties of an existing scale	Exclude	Presents a scale based on an existing model of recovery.
CORRIGAN2002	Electronic	Intervention study and focus groups.	Exclude	Looks at the themes included in an existing intervention manual, then applies these themes to people who have taken part in the intervention.
CORRIGAN2004	Hand search (author-based search)	Factor analytic study of 1,824 persons with serious mental illness.	Exclude	Looks at the factor structure of the RSA – use for ref check.
CORRIGAN2005	Electronic	Overview to book on recovery	Exclude	Discussing meaning / definition of recovery and not a concise model e.g. recovery can happen spontaneously,

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
				recovery can occur with proper treatment and recovery gives hope.
COURSEY1997	Electronic	Literature review	Exclude	Doesn't present a model of recovery.
COURSEY2000	Electronic	Uses 3 psychological frameworks to understand the views of consumers regarding mental illness	Exclude	Is not specifically focused on recovery and uses existing psychological frameworks.
CROWE2005	Citation	Analysis of psychotherapy sessions using qualitative methods.	Exclude	Focuses on the experience of one women regarding her treatment in psychotherapy.
DAVIDSON1997	Electronic	Semi-structured interviews with 66 people who had been hospitalised due to psychiatric problems	Exclude	Analysis of the interviews in the current paper focuses purely on the sense of self.
DAVIDSON2004	Electronic	Opinion article	Exclude	Doesn't contain a model of recovery.
DAVIDSON2005	Electronic	Literature review	Exclude	Doesn't present an original model of recovery.
DAVIDSON2005B	Electronic	Literature review	Exclude	Reviews the existing literature, does not present an original model of recovery.
DAVIDSON2006	Electronic search	Literature review	Exclude	Focuses on a strengths-based approach for viewing a client with a mental health problem.
DAVIDSON2006A	Electronic search	Opinion article	Exclude	Focuses on the concerns about implementing a recovery orientated system.
DAVIDSON2007	Electronic	Literature review	Exclude	Presents an existing model of recovery
DAVIDSON2007	Electronic	Literature review	Exclude	Does not present a model of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
DAVIDSON2007	Electronic search	Description of system transformation and building up of core principles and values of a recovery orientated system.	Exclude	Focuses on the experience of implementing existing models and themes of recovery in practice.
DAVIDSON2008A	Electronic	Literature review	Exclude	Looks at existing models and definitions of recovery in schizophrenia.
DEEGAN1988	Hand search (author-based search)	Narrative of recovery experience	Exclude	Presents a narrative of her experience and does not draw any themes or synthesis of this narrative.
DEEGAN2002	Citation	Individual narrative	Exclude	Presents a model of recovery based on her individual experience and narrative.
DICKSON2008	Electronic	Systematic review of interventions and framework mapping.	Exclude	Presents an existing model of recovery.
DoH2003	Electronic	Policy document	Exclude	Implementation guide for STR workers. Useful for manual and adding an implementation guide to the manual.
DoH2007	Electronic	Policy document	Exclude	Implementation guide
DoH2008	Electronic	Policy document	Exclude	Looks at the competencies of staff.
DORRER2008	Electronic	Overview article and opinion paper.	Exclude	Only looks at staff competencies and not at a conceptual model of recovery.
DRAKE2000	Electronic	Editorial	Exclude	Presents an introduction to the special volume on recovery.
EMSLIE2006	Electronic	Semi-structured interviews with men experiencing depression	Exclude	Interviews focus on the experience of depression and masculinity and not on the experience of recovery from depression.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
ENNALS2009	Electronic	Case study	Exclude	Looks at that use of a measure in practice and in understanding personal narratives.
FALLOT2002	Electronic	Intervention study	Exclude	Doesn't present a model of recovery
FARDELLA2008	Electronic	Literature review of the existing themes in recovery	Exclude	Doesn't present an original model of recovery.
FARKAS2005	Electronic	First person accounts and empirical research	Exclude	Model of the service orientation.
FARONE2004	Electronic	Literature review	Exclude	Does not present a new model of recovery.
FAVA2007	Electronic	Literature review of recovery in depression	Exclude	Focuses on remission and relapse and does not present a model of personal recovery.
FEKETE2004	Electronic	Personal narrative	Exclude	Focuses on the personal narrative on one individual with no synthesis of the literature or of multiple accounts.
FELTON2005	Electronic	Ethnographic study including questionnaires, narratives and observation.	Exclude	Looks at the experience and evaluation of a consumer-run service.
FERGUSON2004	Electronic	Description of clubhouse service	Exclude	Describes a recovery focused service and not a recovery model
FISHER2004	Hand search (web)	Literature review and action strategy	Exclude	Presents an action plan for mental health services based on an existing model of recovery.
FISHER2005	Hand search (web)	Model based on previous research	Exclude	Model has already been published in an earlier report.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
FISHER2006	Hand search (web)	Teleconference with peers	Exclude	Presents an existing model of recovery (empowerment model)
FISHER2009	Electronic	Psychometric properties of an existing recovery scale	Exclude	The recovery scale is based on an existing model of recovery.
FODERARO2000	Electronic	Opinion article	Exclude	Population not relevant – survivors of childhood trauma.
FORQUER2001	Electronic	Description of self-help interventions	Exclude	Doe not present a model of recovery but described existing services.
FOWLER2009	Electronic	RCT intervention study	Exclude	Clinical recovery following CBT
FRAK2005	Hand search (web)	Report into pilot recovery sites	Exclude	Presents an overview of recovery – use for reference check
FREE1998	Electronic	Pre-post intervention study	Exclude	Focuses on clinical recovery and correlating measures of clinical recovery.
FRESE1997	Electronic	Literature review focusing on the history of the recovery movement.	Exclude	Does not present a new model of recovery
FRESE2001	Electronic	Literature review	Exclude	Does not present a new model of recovery.
FRESE2009	Electronic	Reviews treatment approaches for schizophrenia in light of the SAMSHA 10 components of recovery.	Exclude	Present an existing model of recovery.
GAVOIS2006	Electronic	Semi-structured interviews with family members who care for and support a person with a mental illness.	Exclude	Presents a model of family support and not of recovery
GAWITH2006	Electronic	Literature review	Exclude	Reviews the history of the recovery movement in New Zealand. Use for PhD.
GIBBS2007	Electronic	Literature review	Exclude	Doesn't present an original model of

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
				recovery.
GILL2006	Electronic	Editorial	Exclude	Does not present a model of recovery
GINGERICH2005	Electronic	Book chapter including a review of the literature regarding illness management	Exclude	The chapter evaluates an illness management programme and not a model of recovery.
GLYNN2006	Electronic	Literature reviews which evaluates family interventions against recovery criteria	Exclude	Does not present a model of recovery but presents existing definitions. Includes a checklist of what recovery orientated interventions should include. Use in the intervention review.
GOLDBERG2005	Electronic	Qualitative study assessing issues people have faced regarding gaining employment.	Exclude	Study focuses on issues concerned with employment.
GOVE2004	Electronic	Literature review	Exclude	Doesn't present an original model of recovery.
GREENFIELD1989	Electronic	Semi-structured interviews will people recovering from mental illness.	Exclude	Focuses on insight and not on recovery.
GRIFFITHS2008	Electronic	Overview of SPN work	Exclude	Editorial / commentary
GRIFFITHS2009	Electronic	Literature review.	Exclude	Reviews existing models of recovery.
GRUHL2005	Electronic	Literature review	Exclude	Reviews existing models of recovery.
HAERTL2007	Electronic	Evaluation of a peer support / housing service	Exclude	Doesn't present a model of recovery, but evaluates a recovery-focused peer support service.
HALL2000	Electronic	Opinion and discussion article	Exclude	Doesn't present a model of recovery, instead focuses on the roles of the family in a persons recovery.
HALL2008	Electronic	Book chapter	Exclude	Summarises HALL2008B book

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
HALL2008A	Electronic	Book chapter	Exclude	Focuses on assessment – use for review
HALL2008B	Electronic	Book on care planning in mental health to promote recovery	Exclude	Reference is for the whole book, included relevant chapter.
HAPPELL2008	Electronic	Focus groups.	Exclude	Focuses on the factors that facilitate and hinder recovery at the service level. May be more useful for focus group topic guides.
HAPPELL2008B	Electronic	Focus groups	Exclude	Focuses on the barriers to recovery and does not present a model of recovery. Might be useful for focus groups
HARDIMAN2008	Electronic	Survey of health professionals	Exclude	Looks at the implementation of a pre-existing recovery model in different groups of staff.
HARVEY2009	Electronic	Literature review and opinion article	Exclude	Focuses on clinical recovery.
HATCHARD2003	Electronic	Individual narrative of the experience of bipolar disorder	Exclude	Person account of recovery does not include any synthesis.
HAWKES2007	Electronic	Opinion article	Exclude	Does not present a model of recovery – discussion paper.
HCC2008	Hand search (web)	Review of acute services	Exclude	Does not present a model of recovery but reviews acute services with reference to recovery outcomes.
HIGBY2002	Hand search (web)	Commentary and opinion piece	Exclude	Lists the eight steps to recovery from the perspective of the service.
HIGGINS2007	Electronic	Literature review	Exclude	Presents existing models of recovery. Use for ref check.
HITLOW2007	Electronic	Commentary	Exclude	Population not relevant – looking at substance misuse and addiction services.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
HOFFMAN2002	Electronic	Cohort study with case studies of 4 people.	Exclude	Looks at predictors of clinical recovery and remission.
HUXLEY2009	Electronic	Semi-structured interviews.	Exclude	Focuses on the competencies and values of STR workers.
JACKSON2008	Electronic	Opinion article / commentary	Exclude	Commentary – also doesn't include a model of recovery.
JACOBSON2003	Electronic	Workgroup of stakeholders defined and operationalised recovery	Exclude	Includes themes but does not present easily in the form of a model.
JACOBSON2004	Electronic	Book on recovery written based on personal experience and literature review.	Exclude	Does not include a succinct model of recovery. Describes existing models and the work of the recovery work group.
JOHNSON2004	Electronic	Semi-structured interviews with women using crisis houses and acute hospital wards	Exclude	Focuses on the experience of services and not on a model of recovery.
JONES2007	Electronic	Literature review focusing on African American mental health needs and services.	Exclude	Gives an overview of recovery definitions.
JONES2008	Electronic	Narrative project	Exclude	Gives a description of a narrative project for young people with psychosis.
KEKS2003	Electronic	Literature review and discussion article.	Exclude	Does not present a model of recovery
KHAN2008	Electronic	Literature review	Exclude	Presents existing models of recovery.
LARSEN2007	Electronic	Ethnographic study	Exclude	Focuses on the experience of early intervention services and does not present a model of recovery.
LEIBRICH1998	Electronic	Book chapter detailing a personal narrative	Exclude	Presents a personal story organised around 21 tools of recovery.
LESTER2006	Electronic	Editorial feature	Exclude	Presents existing models of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
LEUCHT2006	Electronic	Literature review	Exclude	Overviews existing models – use for a reference check.
LLOYD1999	Electronic	Literature review	Exclude	Does not include a model of recovery – describes existing definitions.
LLOYD2004	Electronic	Literature review	Exclude	Present an overview of existing models and definitions of recovery – ref check.
LLOYD2008	Electronic	Literature review	Exclude	Presents existing models of recovery which are organised under three headings. Use for reference check.
LOVELACE2007	Electronic	Evaluation of recovery-focused service	Exclude	Doesn't present a new model of recovery.
LUNT2000	Electronic	Opinion article	Exclude	Doesn't present a model of recovery.
LYSAKER2006	Electronic	Correlational study of 34 narratives against recognised measures	Exclude	Looks at different measures of recovery and not at a recovery model.
MACDONALD2005	Electronic	Phenomenological study of individuals with psychosis attending a recovery group.	Exclude	Focuses on social relationships in first episode psychosis and not specifically on recovery. Use in social paper.
MARKOWITZ2001	Electronic	Longitudinal questionnaire with 610 people using a self-help service	Exclude	Looks at pre-defined elements of recovery and then conducts a factor analysis of these elements using clinical scores.
MARSHALL2007	Electronic	Literature review	Exclude	Focuses on an evaluation of consumer involvement in case management based on existing notions of recovery.
MCCORMACK2007	Electronic	Discussion paper	Exclude	Describes existing models, including the strengths based model. Keep for refs.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
MCGONAGLE2007	Electronic	Overview paper	Exclude	Outlines existing NIMHE model.
MCGRATH2007	Electronic	Individual interviews focused on recovery from mental illness with reference to use and misuse of drug treatments.	Exclude	Focuses on the use of drugs in recovery and does not present a general model.
MCGRUDER2001	Electronic	Personal narrative of lived experience	Exclude	Does not present a model of recovery
MCVANELVINEY2006	Electronic	Literature review and study of implementation.	Exclude	Presents an existing model of recovery.
MEEHAN2008	Electronic	Literature review	Exclude	Reviews existing models and definitions of recovery.
MELVIN2006	Electronic	Review	Exclude	Does not present an original model of recovery.
MENTALHEALTHACT2008	Electronic	Policy report	Exclude	Doesn't look at the concept of recovery.
MENTALHEALTHACT2008	Electronic	Policy document	Exclude	Policy report, does not present a model of recovery.
MENTALHEALTHFOUNDATION2009	Hand search (web)	Evaluation of pilot recovery sites	Exclude	Evaluates a recovery-orientated tool and recovery-orientated services. Uses the DREEM.
MHCC2009	Hand search (web)	Fidelity scales / quality standards	Exclude	Existing models of recovery and team quality standards.
MILLER1997	Electronic	Overview of supported employment service	Exclude	Does not present a model of recovery instead gives an overview of a supported employment service.
MORSE1997	Electronic	Literature review	Exclude	Not specific to mental health also looks at physical illness
MOUNTAIN2008	Electronic	Literature review	Exclude	Presents existing model of recovery

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
				(RESNICK 2005)
MUESER2006	Electronic	Preliminary findings of a controlled trial of illness management, including development of the programme and rationale.	Exclude	Evaluates the illness management and recovery programme. Presents a Conceptual Framework for the programme and not for recovery in general.
MURRAY1996	Electronic	Literature review and overview of Recovery Inc.	Exclude	Presents an overview of Recovery Inc but does not present an original model.
NELSON2001	Electronic	Focus group interviews	Exclude	Focuses on empowerment and uses an existing model of mental health.
NHSEDUCATION2007	Electronic	Literature review and consultation process	Exclude	Quality standards
NO2003	Electronic	Overview – opinion article	Exclude	Not relevant (introduction to special issue).
NOISEUX2009	Electronic	Protocol for using qualitative methods to develop a model of recovery in mental health	Exclude	Presents a protocol for further work and looks at an existing model of recovery (Noiseux2008)
NORGEN2007	Electronic	Pre-post intervention study	Exclude	Focuses on measuring clinical recovery.
OCONNOR2007	Electronic	Literature review	Exclude	Doesn't present an existing model – use for ref check.
OHAGAN2004	Hand search (author-based search)	Guest editorial	Exclude	Doesn't present a model of recovery, gives an overview of existing models including relevant to culture and ethnicity.
OHAGAN2008	Electronic	Narrative review and opinion article	Exclude	Presents an overview of recovery – check references.
OHAGAN2009	Hand	Past research and personal experience.	Exclude	Focuses on a model of service delivery

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
	search (web)			
PAQUETTE2005	Electronic	Editorial including an individual narrative	Exclude	Only includes an individual narrative about the recovery experience.
PARKS2007	Electronic	Opinion article	Exclude	Describes the implementation of a mental health service.
PASCARIS2008	Electronic	Evaluation and overview of a project assessing the implementation of a work and recovery project	Exclude	Focuses on organisation change with the programme based on an existing model of recovery.
PEEBLES2009	Electronic	Evaluation study	Exclude	Evaluates the impact of a staff training intervention based on an existing recovery model.
PERNICE-DUCE2009	Electronic	Semi-structured interviews with participants using clubhouse services.	Exclude	Paper focuses on the social support. (Send to JT)
PERRY2007	Electronic	Individual semi-structured interviews using IPA for the analysis	Exclude	The interviews focus specifically on hope in the process of recovery from a first episode of psychosis. Use for hope review
PETCH2008	Electronic	Overview of the narratives project.	Exclude	Presents an overview of the SRN narratives project which is included in more detail in another article.
PETTIE1999	Electronic	Literature review	Exclude	Paper only focuses on two aspects of an existing recovery model – identity and meaning.
PILGRIM2008	Electronic	Literature review	Exclude	Does not present a new model or framework of recovery, lists existing recovery models
PITT2006	Electronic	Semi-structured interviews with 7	Exclude	Paper not original (is reprinted in fuller

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
		people who had experience of psychosis.		format in PITT2007)
PITTS2004	Electronic	Literature review	Exclude	Presents existing models and definitions of recovery. Use for reference check.
PRABHU2007	Electronic	Cohort study assessing the effects of a recovery-based outreach program	Exclude	Describes the collaborative recovery model.
PROVENCHER2007	Electronic	Narrative review and development of a new stress framework.	Exclude	Does not present a framework for recovery, framework focuses on stress in the recovery process.
RALPH2000A	Hand search (web)	Literature review	Exclude	Presents existing models of recovery
RALPH2002	Hand search (web)	Literature review	Exclude	Doe not present an original model of recovery. Use for ref check as comprehensive review
RALPH2005	Electronic	Reviews existing models and definitions of recovery	Exclude	Discusses existing models – use for reference check. Includes a write-up of the recovery advisory group model and Dornan's model which is not available in print elsewhere.
RALPH2005A	Electronic	Whole book	Exclude	Various chapters have been included.
RAMON2009	Electronic	Review literature on policy and practice	Exclude	Paper focuses on implementation of a recovery model / approach
RAMSEY2009	Electronic	Individual narrative	Exclude	Does not include a model of recovery.
RAPP2006	Electronic	Review of recovery definitions	Exclude	Discusses existing models – use for reference check.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
READ2009	Electronic	Semi-structured interviews with consumer service providers	Exclude	Focuses on the effects of peer support and volunteering.
REISNER2005	Electronic	Literature review of existing models of recovery	Exclude	Presents only existing models of recovery. Use for ref check.
RESNICK2004	Electronic	Regression analysis of the factors associated with a recovery orientation.	Exclude	Only assesses the factors associated with an existing model of recovery (use for hope review). RESNICK2005 original model
RICKWOOD2006	Hand search	Consultation process	Exclude	Focuses on a model of mental illness prevention.
ROBERTS2004	Hand search (web)	Literature review	Exclude	Presents existing models of recovery, use for reference check, also for PhD as mentions ethnicity and diversity.
ROBERTS2008	Electronic	Literature review	Exclude	Presents existing models of recovery.
RODGERS2007	Electronic	Literature review linking EBP with recovery.	Exclude	Presents existing models of recovery, use for ref checks.
ROE2007	Electronic	Commentary	Exclude	Commentary
ROE2008	Electronic	Book chapter giving a review of key developments of the “era of recovery” in schizophrenia	Exclude	No concise model of recovery, discusses the meaning of the word
ROE2009	Electronic	Evaluation of the illness management and recovery intervention.	Exclude	Focuses on the evaluation of the intervention and not on a model of recovery.
ROGERS2007	Electronic	Conference consultation method involving 34 psychiatrists currently implementing a recovery approach.	Exclude	Focuses on barriers to the implementation of a recovery orientated service.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
RUDGE2001	Electronic	Discourse analysis using the literature as an analytic framework	Exclude	The focus isn't specifically on recovery. Does not present a model.
SAENGER1970	Electronic	Baseline characteristics of psychiatric admission, pre-post admission	Exclude	Doesn't present a model of recovery
SCHINKEL2007	Electronic	Literature review and focus group study.	Exclude	Focuses on the staff competencies required for a recovery-focused service.
SCHMOLKE2005	Electronic	Conference paper	Exclude	Presents existing definitions and models of recovery in relation to wellbeing.
SECKER2002	Electronic	Semi-structured interviews	Exclude	Focuses on recovery in the context of a supported employment intervention.
SELLS2005	Electronic	Personal narratives	Exclude	Does not present a model of recovery, focuses on personal narratives.
SHANLEY2007	Electronic	Literature review and discussion article	Exclude	Paper presents a new model of nursing – Recovery alliance theory. Recovery is part of the model rather than being a model of recovery.
SHEPHERD2008	Electronic	Literature review	Exclude	Present an overview of existing models and definitions of recovery – ref check.
SHEPHERD2008	Hand search (author-based search)	Literature review and policy document	Exclude	Present an overview of existing models and definitions of recovery – ref check.
SHILOH2007	Electronic	Implicit and explicit measures using questionnaires to measure people's	Exclude	Does not focus on mental health. Looks at health locus of control in lay people's

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
		health beliefs and attributions		explanations and attributions of recovery.
SIEBERT2000	Electronic	Individual case study	Exclude	Focuses on the therapeutic process of just one individual and how the therapy contributed to her recovery.
SILVERSTEIN2008	Electronic	Literature review	Exclude	Presents existing models of recovery. Very comprehensive and also has an organising framework – use for refs.
SKARSATER2006	Electronic	Secondary analysis of semi-structured interviews using an existing framework.	Exclude	The analysis fits an existing framework to the quotes and does not come up with an original model based on the data
SLADE2007	Electronic	Editorial	Exclude	Doesn't present a model of recovery
SLADE2008	Electronic	Literature review	Exclude	Gives an overview of existing models and recovery movements. Use for reference check.
SOLOMON2004	Electronic	Literature review	Exclude	Presents only existing models of recovery.
SPANDLER2007	Electronic	Qualitative case studies	Exclude	Focuses on the effectiveness of arts therapy in a person's recovery.
SPANIOL2000A	Electronic	Opinion article	Exclude	Only provides guidance on recovery practice in the context of arts therapy.
SPN2007	Electronic	Collection of articles that were presented at the recovery study day.	Exclude	Doesn't present any new models of recovery. Include for PhD as includes some BME perspectives on recovery.
SRN2007	Electronic	Literature review and consultation	Exclude	Focuses on service values, training and tasks. Use for standards.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
SRN2008A	Hand search (web)	Overview of the outside the box BME project	Exclude	Includes an overview of the progress and process of the project, also includes some individual quotes but does not present a model.
SRN2008B	Hand search (web)	Overview of the outside the box BME project	Exclude	Includes an overview of the progress and process of the project, also includes some individual quotes but does not present a model.
SRN2008C	Hand search (web)	Overview of the outside the box BME project	Exclude	Doesn't present a model of recovery, instead reports on the project. Include for PhD
STEURY2004	Electronic	Commentary	Exclude	Population not relevant.
STEVENSGUILLE2003	Electronic	Opinion article	Exclude	Doesn't present a model of recovery. Focuses on nurses.
STEVENSON1961	Electronic	Literature review with case study as examples	Exclude	Does not present and original model of recovery.
STICKLEY2006	Electronic	Opinion article based on a narrative review of the literature	Exclude	Focuses on risk and is not specific to mental health recovery.
STOCKS1995	Electronic	Opinion article	Exclude	Does not present a model of recovery.
STOTLAND2008	Electronic	Literature review by clinician and consumer with Bipolar disorder	Exclude	Focuses on existing models of personal recovery – use second half of the paper for ref check.
STOTT2008	Electronic	Opinion article	Exclude	Does not present a model of recovery.
TANENBAUM2006	Electronic	Literature review and opinion article	Exclude	Discusses the link between evidence based practice and existing ideas of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
TILL2007	Electronic	Literature review	Exclude	Presents existing models and definitions of recovery. Use for ref check.
TILSEN2008	Electronic	Literature review	Exclude	Present existing models of recovery.
TIMONEY2007	Electronic	Overview of the women's BME project	Exclude	Includes an overview of the progress and process of the project, also includes some individual quotes but does not present a model. Include for PhD
TORGALSBOEN2001	Electronic	Cohort study using semi-structured interviews and surveys.	Exclude	Looks at the correlation between clinical scales and recovery following an intervention.
TORREY2000	Electronic	Literature review	Exclude	Reviews existing models of recovery and focuses on services providing hope inspiring relationships.
TOWNSEND2003	Electronic	Literature review	Exclude	Presents existing definitions of recovery.
TSE2004	Electronic	Literature review and case study	Exclude	Does not present a model of recovery.
TURNER2002	Electronic	Review of the literature	Exclude	Does not present a model of recovery, instead focuses on a number of elements in recovery.
TURNERCROWSON2002	Electronic	Literature review focusing on a UK perspective	Exclude	Does not present an original model of recovery.
VALINEJAD2008	Electronic	Intervention study (pre-post observations)	Exclude	Presents an evaluation of an intervention based on an existing model of recovery.
VANOS2002	Electronic	Literature review	Exclude	Doesn't present a model of recovery.
VASSALLO1998	Electronic	Case study of narrative group therapy sessions	Exclude	Doesn't have a model of recovery.

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
WALKER2006	Electronic	Narrative review and opinion article	Exclude	Describes exiting models of recovery and their relationship to social construction.
WALSH1996	Electronic	Personal narrative	Exclude	Details a personal account of lived experience without any synthesis or analysis.
WARNER2009	Electronic	Literature review	Exclude	Presents existing models of recovery and whether current research is supporting the themes and aspects of these models.
WARREN2000	Electronic	Describes the development of a recovery model for services	Exclude	Recovery appears to be just one part of the overall model rather than it being a model of recovery.
WHITE2005	Electronic	Literature review	Exclude	Compares addiction and mental health fields, unclear whether any model developed would relate to either field or both.
WHITEWELL1999	Electronic	Qualitative study	Exclude	Focuses on the opinion of one mental health professional.
WHITLEY2005	Electronic	Semi-structured interviews with people with lived experience of mental illness living in an area undergoing urban regeneration	Exclude	The paper focuses on the effects of urban regeneration on a person's mental health and their recovery. Use for social paper.
WHITLEY2008	Electronic	Focus groups	Exclude	Looks at the role of communities in supporting mental health recovery and does not present a model of recovery itself.
WILKINSON1997	Electronic	Individual semi-structured interviews	Exclude	Focuses on aloneness in the context of depression and recovery. Does not

Study ID	Search Source	Study design	Included /Excluded	Reason for exclusion
				present an overall recovery model.
WILKNISS2009	Electronic	Literature review	Exclude	Reviews current models of recovery.
WISDOM2008	Electronic	Thematic analysis of qualitative interviews and personal stories	Exclude	Focuses on just identity in recovery
WOODSIDE2005	Electronic	Semi-structured interviews with people living with mental illness	Exclude	Focuses on success in vocation and is not specific to recovery.
YANGARBERHICKS2004	Electronic	Literature review	Exclude	Unsure – does this count as a model, doesn't create a new model but describes the recovery model in relation to Christianity.
YOUNG2005	Electronic	Evaluation of a consumer-led interventions	Exclude	Evaluates a recovery focused intervention.
YOUNG2008	Electronic	Mixed methods study – survey and semi-structured interview	Exclude	Only focuses on risk-taking.

Appendix 4: Final Conceptual Framework of Recovery

Recovery Processes	
1st and 2nd Order	**3rd and 4th Order**
1. Connectedness	
1.1. Peer support and support groups	
	1.1.1. Becoming a peer support worker or advocate
1.2. Relationships	
	1,2,1. Establishing new relationships 1.2.2. Building on existing relationships 1.2.3. Intimate relationships
1.3. Support from others	
	1.3.1. Social support 1.3.2. Active or practical support 1.3.3. Support from professionals
1.4 Being part of a community	1.4.1 Contributing and giving back to the community 1.4.2 Membership of community organisations 1.4.3 Becoming an active citizen
2. Hope and optimism about the future	
2.1.Hope inspiring relationships	
	2.1.1 Role models
2.2. Motivation to change 2.3. Belief in possibility of recovery 2.4. Positive thinking 2.5. Having dreams and aspirations	
3. Identity	
3.1. Dimensions of identity	
	3.1.1. Cultural identity 3.1.2. Sexual identity 3.1.3. Ethnic identity
3.2. Rebuilding/ redefining a positive sense of self	
	3.2.1. Self-esteem 3.2.2. Acceptance 3.2.3.Self-confidence and self-belief
3.3. Overcoming stigma	
	3.3.1. Self-stigma 3.3.2. stigma at a societal level
4. Meaning and purpose	
4.1. Meaning of mental illness experiences	
	4.1.1. Accepting or normalizing the illness
4.2. Spirituality (including development of spirituality)	

4.3. Quality of life	
	4.3.1. Wellbeing
	4.3.2. Meaningful structured activities
	Paid or voluntary work
	Recreational and leisure activities
	Education
	4.3.3. Meeting basic needs
4.4. Meaningful life and social goals	
	4.4.1. Active pursuit of previous or new life and social goals
	4.4.2. Identification of previous or new meaningful life and social goals
4.5. Meaningful life and social roles	
	4.5.1. Active pursuit of previous or new life and social roles
	4.5.2. Identification of previous or new meaningful life and social roles
4.6. Rebuilding of life	
	4.6.1. Resuming with daily activities and a daily routine
	4.6.2. Developing new skills
5. Empowerment	
5.1. Personal responsibility	
	5.1.1.self-management
	Self-help
	Coping-skills
	Managing symptoms
	Maintaining good health and wellbeing
	5.1.2.Positive risk-taking
5.2. Control over life	
	5.2.1.choice
	5.2.2 knowledge and information
	Knowledge about illness
	Knowledge about treatments
	Information for families and communities
	5.2.3. Regaining independence and autonomy
	5.2.4. Self-determination
	5.2.5. involvement in decision-making
5.3. Focusing on strengths	

Appendix 5: Focus group topic guide

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KING'S College LONDON

Qualitative study: Building an understanding of recovery-orientated practice in community-based mental health services in England: Service user perspectives.

Service user focus group - Topic guide

The aim of this study is to investigate and explore the perception of individuals regarding the recovery-orientation of community mental health teams and to learn about the participants perspectives on what helps or doesn't help their recovery. As this is an investigative study, we wish to encourage individuals to discuss their views, attitudes, experiences and perceptions in an open way to ensure we include a diversity of responses which may be important to the study.

Pre-focus group: Participants will have been sent an information pack in advance, containing an information sheet. Participants will be given the chance to ask questions, and will then sign their consent forms before the focus group. When signing the consent form, go over confidentiality (e.g. that everything will remain confidential unless they disclose anything indicating risk of harm to self or other.)

1. Introduction (5 minutes)

Aim – to introduce the researchers and the research and to welcome people into the group

- Introduce self and explain why two facilitators (Assisting in organising, note taking and time keeping)

- Introduce the study and purpose of study - why are we here: E.g. *we are interested in how mental health services can help people to live the life they want to live… Throughout the group we will be asking questions about what it means to be well or recover, what ways services help or do not help people in their recovery journeys and*

what things would people like to change about mental health services to better help with their recovery.

- Details about participation
    i. Participation is **voluntary**, stress consent.
    ii. Tape Recording
    iii. Confidentiality within the group, how will results be reported and used.
    iv. No need to share personal experiences unless they want to
    v. Timing of the group (1.5 hours) – could mention clock if using one
- Explain there are **no right or wrong answers** stress we are interested in all opinions, stories and experiences, and in a range and diversity of answers
- Interested in **individuals** and what they have to say
    i. *"We want to hear from as many people as possible, even if you think your view has already been expressed, we would still like to hear from you. "*

- Basic Ground rules
    i. One person speak at a time – mention tape recorder
    ii. Mobile phones on silent?
    iii. No need for everyone to agree or reach a consensus as a group. Stress individuality and diversity again
    iv. Naming staff – "*When talking about your experiences we do not need to know the names of any staff members, although it would be helpful if people could tell us the role of the staff member e.g. psychiatrist, psychiatric nurse, peer support worker etc."*
- Any questions?

2. <u>Participant introductions (5 mins)</u>

Aims – to get everyone to introduce themselves and feel at ease in the group

- Ask everyone to introduce themselves by saying their name and one thing they like to do

3. <u>Starter questions. (10mins) (Start recording)</u>

Aims – to understand what recovery or wellness means to individuals and the group.

Framing statement: *There are lots of different views and individual stories relating to recovery we are interested in all your different opinions, experiences and stories and would like to begin by asking …….*

- What does recovery mean to you
    i. Does anyone have anything to add?
    ii. Anyone agree or disagree?
    iii. Why?
    - **Prompts**

- **Connectedness and relationships**
- **Hope and optimism for the future**
- **Identity and rebuilding a positive sense of identity**
- **Meaning and purpose in life (including meaning in the experience of mental ill health)**
- **Empowerment and gaining control**

Framing statement: *we've heard some really interesting views about what recovery or being well means to people in the group. Then mention the diagram and this is what other people who use mental health service have said recovery means to them*

iv. Does anyone have anything to add?
v. Anyone agree or disagree?

4. <u>Facilitating factors (25 mins)</u>

Aims – to understand what features or factors of mental health services are perceived to support an individual's recovery journey.

Framing statement: *Thank you for all of your opinions. We'd now like to focus on the role of mental health services in you recovery. Some people may have had experiences of services*

supporting them in their recovery journeys, whereas other people may have had different experiences. We would like to hear all of these experiences and opinions today but would like to start by asking…….

How has your community mental health worker/team helped or supported you in your recovery?

- **Probes**
  i. Why has that helped
  ii. Why is that important
  iii. That's something we're definitely interested in hearing more about. What can any of you tell us about that?
  iv. List some areas or examples (**See prompts below**) such as good working relationships, positive aspects of staff, treated as an individual etc.
  v. Refer back to discussion on what recovery means e.g. what about helping you to develop hope etc.
  vi. Recap and ask what other members of the group think

- **Prompts**

We've heard that (add examples from below) can be helpful in some people's recovery, we'd like to hear about some of your stories and experiences.

- **Working in partnership:** *Are you able to work in partnership with your community mental health team?*
- **Decision making:** *Are you involved in making decisions with your community mental health worker/team about the care they provide?*
- **Assessment:** *When you have an assessment, are you asked about your strengths, hopes and aspirations?*
- **Goal setting:** *Able to set goals which may include taking some risks*
- **Coping skills** *Has your mental health team helped you to learn self-management techniques and coping skills to support your recovery?*

- **Relationships** - *maintaining and building new relationships, accessing facilities in your local community?*
- **Staff values and attitudes:**
- **Individuality:** *Do you feel that your mental health worker(s) treats you as an individual (Race, culture and ethnicity taken into account, culturally sensitive and appropriate services)*

5. Barriers (25 mins)

Aims – to understand what features or factors of mental health services are perceived as barriers to an individual's recovery journey

Framing statement: *We've heard all about the ways mental health teams can support someone's recovery, I would now like to ask about different and negative experiences of mental health services and in particular……*

- **What about the ways that your community mental health worker/team doesn't help or support you in your recovery?**

- **Probes**
    i. Why didn't that help
    ii. How do others feel about that
    iii. That's something we're definitely interested in hearing more about. What can any of you tell us about that?
    iv. List some areas or examples (**See prompts below**), such as staff not having time, not having a say in treatment, not being treated like an individual etc. and ask if the group agrees, disagrees?
    v. Refer back to what recovery means, how did that have an impact on these areas?
    vi. Recap and ask if there is anything else

- **Prompts**

- **Working in partnership:** *Working and relating to staff*
- **Decision making:** *Involvement in decision-making and choice e.g. Are you involved in making decisions with your community mental health worker/team about the care they provide?*
- **Assessment:** *Assessments that focus on the negative and only on needs.*
- **Goal setting:** *Are you able to set goals and talk about taking risks?*
- **Coping skills:** *Lack of opportunities to learn skills.*
- **Relationships** *Has your mental health team helped you to maintain and build new relationships, or access facilities in your local community?*
- **Staff values and attitudes:** *Does your mental health worker(s) hold values and attitudes that get in the way of your recovery?*
- **Individuality:** *Do you feel that your mental health worker(s) treats you as an individual (Race, culture and ethnicity, lack of culturally appropriate services, explanatory models.)*

6. <u>Areas of change (15 mins)</u>

Aims – to get the group to think about ways they would change or improve their mental health team or worker and to get a range of suggestions and changes.

Framing statement: *we've been hearing some really interesting views about the way mental health teams can have an impact on recovery, and in particular about some of the ways that mental health services are not helping you in your recovery*

- **What could your community mental health worker/team be doing differently to better support your recovery?**

- **Probes**
  i. How do you think that would help your recovery
  ii. Why do you think that
  iii. Referring back to discussion on the meaning of recovery – are there any ways your team could help with (pick a feature that hasn't been discussed)
  iv. Do others agree or disagree with the suggestion
  v. Recap and ask if there is anything else from the group

vi. Examples?

vii. (Probes based on the answers given for the facilitators and barriers, examples may include culturally sensitive and appropriate services, treating people as individuals, working in partnerships, involvement in decisions and choice over services, values of staff etc.)

7. Reflections and ending the group (5 minutes)

Aim – to bring the group to a close and to get any last perspectives or opinions from group members.

- Warn people when time is coming to an end
- Recap on the areas that have been discussed e.g. what recovery means, how teams help and do not help recovery and areas for change.
- Ask if there are any final thoughts
- Thoughts on the group and the day
- Thank people for their contributions
- **Any questions?**
- Payment.
- What happens next: Refer people to the website and newsletter.

Appendix 6: Individual interview topic guide

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at The Maudsley

Health Service & Population Research Department
Section for Recovery

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KING'S College LONDON

Semi-structured interview topic guide:

- Background about the study and purpose of the interview
- Confidentiality
- Disclosing information

Introduction

What does the person like? Tell me a little bit about yourself, your experiences

Section 1) Personal stories:

What does recovery or wellness mean to you?

- What is your story or personal experience of recovery?

Has your idea of what it means to be well or in recovery changed over time / due to your experiences

- How?

Refer to Conceptual Framework and focus groups:

1) CHIME
2) Spirituality, collectivist identities, cultural factors, community, stigma and discrimination

How might recovery / wellbeing be seen by your community

Section 2) What helps and hinders?

What has helped you in your recovery?

- Stories of helpful people, places, etc.
- Who or what supports you when things aren't going so well?
- What are the most important steps?
- Personal theories of why things helped

What can make being well or in recovery harder for you?

- Are there situations which make you feel worse?
- Are there things which make recovery not possible?
- Levels: Service-level, staff-level, societal –level

Do you think the things that help or hinder recovery are different for black individuals?

- How, why? Why not?
- Issues of stigma within the community, how this may or may not impact on their sense of self / identity and on their recovery
- Issues of racial discrimination (in wider society and in services) how this may or may not impact on their sense of self / identity and on their recovery

Section 3) Impact of MHS

How have mental health services helped or not helped with your recovery

- Personal stories of recovery within the mental health service (mhs)
- Are there any ways that mhs have been helpful with your recovery?
- Are there any ways that mhs have held back your recovery?

Section 4) Should MHS be different?

What would help you live the life you want to lead?

- Do/Can mhs provide these things?
- What could mhs do to help you stay well
- What things you change (if any) about mhs?

What difference (if any) being black makes to the experience of the mental health system?

- Do service need to be different?
- How, why?

Final Dream question

If you didn't have a mental health problem would you change anything?

- What would you like to do / be?
- How have mhs helped with these goals?

Any final thoughts or comments about your experiences or anything we have discussed.

Appendix 7: Full Framework of Recovery Support coding framework

Core category: Identity - Gaining a positive sense of self

1.Defining the self

1.1 Multiple dimensions and identities of a person

1.1.1 Collectivist identity

1.1.2 Individualistic elements of identity

1.2.3 Importance of occupation for defining the self

1.2.4 Religious and spiritual identities

1.2.5 Illness is not the whole identity

1.2 Comparisons with others

1.2.1 Upward and downward social comparisons

/1.2.2 Comparisons with others

/1.2.3 Normalising the experience

1.3 Having a strong identity

/1.3.1 Being able to tell your story

/1.3.2 Being an empowered individual

/1.3.3 Having a greater understanding of yourself and your experience

/1.3.4 Having connections with strong people - positive role models and success stories

/1.3.5 Regaining a sense of worth

2.Negative sense of self

2.1. Societal level threats

2.1.1 Family or community lacking understanding

2.1.2 Social disadvantage

2.1.3 The attitudes of society

2.2.Illness as a threat to identity

/2.2.1 Loss of the person

/2.2.2 Lower self-esteem - having a negative self-image

/2.2.3 Negative experience of the mental health system

3.Continuum of recovery - from returning to the same as before to becoming a new person

3.1 Returning to the same as before

3.1.1 Having the same life as before

3.12 Learning to or starting to enjoy things again

3.1.3 Returning to your old self

3.1.4 Being able to do the same things as before

3.2 Recovery is about change – becoming a new person

3.2.1 Moving forward in life

3.2.2 Development and change in personality

3.2.3 Becoming a new person

3.3 Meaning of recovery depends on meaning of illness

3.3.1 The meaning of recovery

3.3.2 The meaning of the 'illness' experience

3.3.3 Help seeking experience

4. Mental health System level facilitators of gaining a positive sense of self

4.1 Being treated as an individual

4.1.1 Focusing on the whole person

4.1.2 Staff valuing and accepting difference

4.1.3 Valuing the individuals own story

4.2 Support from the right services and professionals

4.2.1 Services are there when you need them

4.2.2 Peer support
4.2.3 Importance of medication as a support
4.2.4 Help to meet your goals and ambition
4.2.5 Help seeking outside of the mental health system
4.2.6 Ensuring the person's basic needs are met
4.2.7 Access to a range of services including talking therapies

4.3 Staff as a facilitator of a positive identity

4.3.1 Communication with staff
4.3.2 Down to the individual qualities of staff members
4.3.3 Having staff members or someone who understands you
4.3.4 Partnership working

5. Facilitators of a positive sense of self beyond the mental health system

5.1 **Individual / intrapersonal level facilitators of a positive identity**

5.1.1 Coping and living with the illness
5.1.2 Hope and optimism - you can recover
5.1.3 Importance of occupation
5.1.4 Planning for the future

5.2 Connecting with people - interpersonal facilitators of a positive identity

5.2.1 Overcoming isolation
5.2.2 Practical support
5.2.3 Sharing the problem
5.2.4 Support from family and friends

5.3 Community and societal level facilitators of positive identity

5.3.1 Race, culture and ethnicity as a support
5.3.2 Overcoming discrimination
5.3.3 Importance of the community
5.3.4 Importance of religion and spirituality
5.3.5 Empowerment - being an empowered citizen

Appendix 8: Intervention Outline Expert Consultation

This consultation is asking for your comments on the outline structure of the REFOCUS Manual. The Manual will be implemented in a randomised controlled trial in adult mental health services in two mental health trusts (South London and Maudsley NHS Foundation Trust and 2gether NHS Foundation Trust) from January 2011.

The Manual is based on the Conceptual Framework of personal recovery (see Consultation 1), and needs to be meaningful to clinicians so it can be successfully implemented in the NHS.
To achieve these aims the Manual is divided into two sections:

1. Core modules: all modules to be implemented by the intervention teams. The core modules use clinical pathway terminology whilst ensuring that the pathway is consistent with a recovery approach. The core modules are organised in this way to ensure that the Manual makes sense to the clinical staff being asked to implement it.

2. Additional modules: each intervention team will be assisted to implement one additional module, spanning the five recovery process domains identified in the Conceptual Framework.

To develop the manual, existing international recovery quality indicators were thematically analysed to identify domains of a recovery-orientated service. For each of the modules, potential intervention areas were mapped on to these domains within the literature. Each of the identified areas was then assessed by the research team for its applicability to the five personal recovery Conceptual Framework domains and its feasibility within the context of the NHS and RCT. The draft Manual outline is on the next page, followed by the consultation questions. An additional table has been included at the end of this document giving more detail, but this does not need to be looked at.

Intervention Manual outline

Introduction

What is personal recovery and clinical recovery? The need to consider staff values and Working Practices. Aims and empirical underpinnings for this manual.

Each team undertakes Modules 1 to 4 and chooses one additional option from Modules 5 to 9.

CORE MODULES

Module 1: Knowledge, values and attitudes

Team-level training covering what recovery means in terms of Principles (e.g. power issues, personal goals, shared decision-making), Processes (e.g. empowerment, hope) and Stages. Consideration of personal values (e.g. role expectations, interpersonal style including hope-inspiring relationships) and their link with recovery orientation in teams. Staff **self-completion of WRAP** and the role of supervision in shaping staff behaviour. A team audit of recovery-related strengths and areas of growth to aid the selection of the additional module.

Module 2: Assessment (Strengths assessment)

Training and supervision support for clinical use of an assessment of personal strengths and natural supports.

Module 3: Care planning (Recovery planning)

Training and supervision support for implementation of a recovery planning tool (e.g. Wellness Recovery Action Planning (WRAP))

Module 4: Interpersonal style (Valuing individuality)

Training in interpersonal skills (e.g. coaching, mentoring, cultural competence) to support positive identity development including cultural, spirituality, sexuality etc.

ADDITIONAL MODULES

Module 5: Connectedness

Training and supervision support for staff to link people with community resources

Module 6: Hope – interventions to promote hope.

An intervention to promote hope (coming out of the hope review).

Module 7: Identity

Training and supervision for supporting the development of a positive identity through the use of narratives and story-telling interventions / tools.

Module 8: Meaning and Purpose (Goal setting)

Training and use of Collaborative Goal Technology to support goal-setting and goal-striving

Module 9: Empowerment

Training and supervision support for positive risk-taking using a shared decision-making tool.

For each module, the emphasis will be placed on delivering the specified tool, intervention, measure etc. in a recovery-orientated way and consistent with the principles covered in Module 1.

Appendix 9: REFOCUS Baseline Assessment

REFOCUS OUTCOME STUDY

Service User Baseline Assessment Booklet

V1 (30.11.10)

REFOCUS Project RCT

Baseline Assessment Checklist – service user

Measure	Yes	No	Comments
1. Eligibility			
2. Consent form			
3. Sociodemographics (SF-SU)			
4. Questionnaire about the Process of Recovery (QPR)			
5. Importance of Services in Recovery (INSPIRE)*			
6. Recovery Fidelity Scale (RFS-SU)*			
7. Client Satisfaction Questionnaire (CSQ-8)			
8. Herth Hope Index (HHI)			
9. Manchester Quality of Life (MANSA)			
10. Mental Health Confidence Scale (MHCS)			
11. Warwick Edinburgh Wellbeing Scale (WEMBWS)			
12. Short Form Health Survey (SF-12)			
13. Camberwell Assessment of Needs (CANSAS-SU)			
14. Client Services Receipt Inventory (CSRI)			
15. National Adult Reading Test (NART)			
16. Brief Psychiatric Rating Scale (BPRS)			

Date(s) of completion:		**Respondent code:**	
Name of researcher:			

* Indicated measures created for the REFOCUS trial and included in this appendix

INSPIRE (Version 3)

People talk about recovery in different ways but one way to think about it is 'living a satisfying and hopeful life'.

This questionnaire asks about how your worker supports your recovery.

Section One (Support) asks about important parts of your recovery and how your worker supports you with them.

Section Two (Relationships) asks about your experience of working with this person.

Please answer all of the questions about ……(name of worker).

If you do not want to answer a question then just leave it blank.

Support section

Please read each question and decide whether it is important to you or not. **If you circle No, then go to the next question down. If you circle Yes, then circle one option in the grey box to rate how much support you get from your worker or if you do not want any support from your worker.**

	An important part of my recovery is…			**I feel supported by my worker with this…**				
S1	Feeling supported by other people	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much

	An important part of my recovery is…			I feel supported by my worker with this…				
S2	Having positive relationships with other people	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S3	Having support from other people who use services	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S4	Feeling part of my community	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S5	Feeling hopeful about my future	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S6	Believing that I can recover	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S7	Feeling motivated to make changes	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S8	Having hopes and dreams for the future	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S9	Feeling I can deal with stigma	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S10	Feeling good about myself	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much

	An important part of my recovery is…			I feel supported by my worker with this…				
S11	Having my spiritual beliefs respected	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S12	Having my ethnic/cultural/ racial identity respected	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S13	Understanding my mental health experiences	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S14	Doing things that mean something to me	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S15	Rebuilding my life after difficult experiences	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S16	Having a good quality of life	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S17	Feeling in control of my life	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S18	Being able to manage my mental health	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much

	An important part of my recovery is…			I feel supported by my worker with this…				
S19	Trying new things	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much
S20	Building on my strengths	No	Yes	Not at all	Not much	Somewhat	Quite a lot	Very much

Relationships Section

Please circle the option that best matches your relationship **with your worker.**

R1	I feel listened to by my worker	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
R2	I feel supported by my worker	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
R3	I feel that my worker takes my hopes and dreams seriously	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
R4	My worker respects me	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
R5	My worker treats me as an individual-more than a ‘diagnosis’ or a ‘label’	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

R6	My worker supports me to make my own decisions	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
R7	My worker keeps hopeful for me even when I feel at my lowest	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Thank you for taking the time to complete this questionnaire

Recovery Fidelity Scale - Service user version

Please rate whether you have experienced any of the following in the last nine months-please circle the option which best matches your experience

1	In the last nine months have staff used coaching skills with you-for example, working with you to find your own ways to meet your goals?	Not at all	Some of the time	All of the time
2	In the last nine months have staff discussed your values and treatment preferences with you?	No	Partly	Fully
3	In the last nine months have staff asked you about your strengths including things you're good at and people who support you?	No	Partly	Fully
4	In the last nine months have staff worked with you to identify your goals?	No	Partly	Fully
5	In the last nine months have staff supported you to work towards your goals?	No	Partly	Fully
6	Have you been involved in a 'service user partnership project', with staff and other service users from the team working together on a project?	No	Yes	

Appendix 10: Data Validation Table

	QPR	CSQ-8	HHI	MANSA	MHCS	WEMBS	INSPIRE Support	INSPIRE Relationships	ICECAP-A	RFS-SU	CANSAS-S (met need)	CANSAS-S (unmet need)	CANSAS-S (no need)
Control Group													
N	43	43	41	39	39	39	42	42	37	38	41	41	41
Skewness	-.47	-.64	.23	-.25	-.68	-.05	-.59	-1.62	-.46	.29	0.68	1.15	-.77
Kurtosis	3.13	5.21	2.84	2.78	3.37	2.71	2.67	7.74	2.69	1.78	2.72	3.64	3.90
Shapiro-Wilk test	0.46	0.11	0.40	0.83	0.16	0.58	0.12	**0.00**	0.27	0.02	0.03	**0.00**	0.13
Intervention Group													
N	38	34	33	33	32	33	36	35	32	32	33	33	33
Skewness	.16	-1.29	.42	-0.2	-.15	-.50	-.60	-.71	0.68	-.10	.91	.65	.26
Kurtosis	2.71	4.89	4.98	3.46	3.07	2.48	2.82	3.16	1.77	1.94	3.61	2.72	1.80
Shapiro-Wilk test	0.29	**0.00**	0.05	0.68	0.63	0.24	0.19	0.03	0.03	0.38	0.03	0.07	0.14
Total													
N	81	77	74	72	71	72	78	77	69	70	74	74	74
Skewness	-.22	-.88	.29	-.16	-.42	.16	-.59	-1.17	-.22	.10	.97	.92	-.28
Kurtosis	3.04	3.71	3.53	3.2	3.20	2.66	2.74	5.43	2.20	1.79	3.97	3.16	2.54
Shapiro-Wilk test	0.31	**0.00**	0.08	0.89	0.28	0.57	**0.01**	**0.00**	0.09	0.02	0.03	**0.00**	0.09

Key: Bold = p<0.01

	BPRS	GAF	HoNOS	CANAS met	CANSAS unmet	CANSAS no need
Control Group						
N	36	50	50	52	52	52
Skewness	-.97	-.59	1.15	.48	.52	-.63
Kurtosis	3.48	2.53	5.22	2.56	3.24	3.46

	BPRS	GAF	HoNOS	CANAS met	CANSAS unmet	CANSAS no need
Shapiro-Wilk test	0.02	0.04	**0.01**	0.11	**0.00**	0.39
Intervention Group						
N	31	47	46	48	48	48
Skewness	1.06	-.31	.21	.70	.34	-.38
Kurtosis	3.170	2.17	2.05	2.99	2.37	2.72
Shapiro-Wilk test	**0.00**	0.23	0.25	0.09	**0.00**	0.79
Total						
N	67	97	96	100	100	100
Skewness	1.02	-.49	.87	.59	.65	-.50
Kurtosis	3.36	2.56	4.59	2.79	3.58	3.12
Shapiro-Wilk test	**0.00**	0.02	**0.00**	**0.01**	**0.00**	0.23

Key: Bold = p<0.01